BECOMING A MOTHER IN THE NICU: A GROUNDED THEORY STUDY

MARION YETMAN

Becoming a Mother in the NICU:

A Grounded Theory Study

by

Marion Yetman, R.N., B.N.

A thesis submitted to the School of Graduate Studies

in partial fulfilment of the course requirements for the degree

of Master of Nursing

School of Nursing

Memorial University of Newfoundland

August, 1999

St. John's Newfoundland

ABSTRACT

Survival rates of very low birth weight (VLBW) infants have improved dramatically. This results in long periods of time in the Neonatal Intensive Care Unit (NICU) for the infant and the parents. The purpose of this study was to examine the process of maternal involvement with their VLBW infants while the infants were in the NICU.

A grounded theory approach was utilized to develop a beginning theory of the mother's involvement with her VLBW infant in the NICU. From a sample obtained from a tertiary care unit serving a provincial population, twelve mothers were interviewed. The substantive theory which emerged "Becoming a Mother in the NICU" defines the process through which mothers proceed as they engage in the mothering role in an unfamiliar environment. It defines three stages in the process: a) caring from the margins, in which the mother as an interested observer experiences a state of anomie, gives over the care of her infant to the professionals; b) shifting the balance, as the baby's condition stabilizes, the mother increases her sense of ownership and responsibility; and c) making progress, where the mother more fully takes on her mothering role.

The findings of this study give a better understanding of some of the conditions that promote or inhibit maternal involvement with their VLBW infants and what that process is like for mothers. Study findings also point to the significant contribution that nurses make to facilitate maternal involvement with their VLBW infants in the NICU.

ACKNOWLEDGMENTS

The researcher would like to acknowledge the contribution of the following people who helped make this study a very worthwhile experience:

Firstly, to the mothers of the very low birth weight infants, who willingly shared their experiences of the Neonatal Intensive Care Unit with me. Their generosity made this project a success.

To the members of my thesis committee: Dr. Shirley Solberg, Dr. Maureen Laryea and Dr. Khalid Aziz, a special thank you. Dr. Shirley Solberg, who taught me my first course in the Master in Nursing program, continued to give me direction and guidance throughout the completion of the program. Dr. Solberg and Dr. Maureen Laryea, co-chairs of my committee, provided insightful direction for the theory development process. Dr. Aziz, whose commitment to family centered care in the neonatal area, inspired my interest in the mother's experience.

To Ms. Cathy Royle, Co-ordinator of the Provincial Perinatal Program, who was instrumental in identifying the participants for this study and acting as the intermediary in making contact with the participants.

Acknowledgment is extended to the Research Committee of the Child Health Program, Association of Registered Nurses of Newfoundland and Labrador, and the Health Care Corporation of St. John's for providing financial support of this research project.

A special thank-you to members of my family; my husband Ken, and my children and study partners, Barry, Gerri, and Margaret for their encouragement and support during the thesis development.

To my parents, Margaret and the late George Furey, who instilled in me and my nine brothers and sisters, the importance of education and who dedicated their lives to ensure that education was a possibility for all, thank you.

TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

Technological advancements in neonatal intensive care units (NICUs) have led to improvements in the survival rates of very low birth weight (VLBW) infants (Hack, Klein, & Taylor, 1995). This improvement in survival, however, is accompanied by long periods of time in the NICUs for infants and their parents. Women with VLBW infants have the challenge of beginning their mothering in an environment that differs greatly from mothers with healthy newborns. They take on their new role, under the supervision of professional caregivers, with infants who are extremely vulnerable, and in an environment that is not only unfamiliar to them but also quite overwhelming. Mother and infant often remain under those conditions for a lengthy period of time. The care of the infants is initially assumed by highly skilled nurses and only gradually is the mother able to take over her infant's care. The purpose of the present study is to examine maternal involvement with a VLBW infant in an NICU environment.

Background

Some factors have been identified that facilitate maternal involvement with their VLBW infants in an NICU environment. Not surprising one of the main factors is the physical condition of the infant. Dramatic improvements in the preterm mortality rate have not been reflected in the premature infant morbidity data. While NICUs have provided the ability to save VLBW infants they also have the power to prolong the pain, suffering, and process of dying for others. As

a group VLBW infants have higher rates of subnormal growth, adverse health conditions, and developmental problems (Hack, Klein, & Taylor, 1995). It has been estimated that rates of brain injury totals approximately 7% for infants 1,500 to 2,000 grams and increases to 20% among the infants 500 to 1,500 grams (Shiono & Behrman, 1995). The early care of VLBW infants is dependent upon highly technical interventions and often the infant's condition remains precarious and unstable for a prolonged period of time. The physical condition of the infant may preclude much early involvement of the mother and she may be hesitant to handle such a tiny and fragile infant. Psychological factors may further inhibit a mother's involvement with her infant. If she perceives that her infant may not survive she may be more hesitant to become involved.

A second factor facilitating maternal involvement has been the policy regarding parental and family visiting in the NICUs. The development of early NICU care was based on rigid rules for infant handling, strict isolation, and the exclusion of any visitors, including parents. Parental involvement in the care of infants in these units was recognized as important (Brimblecombe, Richards, & Roberton, 1978). Almost two decades ago, the work of Klaus and Kennell (1982) on infant bonding suggested early separation could have long term effects on the mother-infant relationship. Since the mid-eighties interest in the effects of parental experiences in the NICU has grown as visiting by parents was encouraged in an effort to promote attachment between infants and their parents. The role of the mothers was especially targeted in developing policies around

these visiting practices. The trend to have parents present in the NICU has continued to evolve over time as the long term hospitalization of VLBW infants emphasized the need to make visiting opportunities more accessible for mothers and fathers. Encouraging parental visiting expanded into the tendency for greater inclusion of parents in the care of their infants until the present day when it is firmly entrenched in NICU policy.

Support from family and friends has been identified by parents as being critical to their ability to cope with the stress of having a preterm baby (Affleck, Tennen, Allen, & Gershman, 1986; Affleck, Tennen, & Rowe, 1991; McHaffie, 1991). Although policies on visiting regulations for family members can vary from institution to institution, grandparents were one of the first groups to be included with parents in family visiting. Support for this initiative has not always been viewed favorably by NICU staff (Blackburn & Lowen, 1986; McHaffie, 1991). This was followed by inclusion of siblings in NICU visiting, an important milestone for parents. The American Academy of Pediatrics Committee on Fetus and Newborn (1985) advocated sibling visitation in the NICU, but it was not until the 1990s that many units instituted sibling visitation. NICU staff felt that with sibling visitation would come disruption in routines, infection control risks, supervisory problems with siblings, and adverse psychological effects on the children (Meyer, Kennally, Zika-Beres, Cashore, & Oh, 1996; Montgomery, Kleiber, Nicholson, & Craft-Rosenburg, 1997). Mothers and fathers see the presence of siblings in the NICU as a return to some normalcy for the family and a way of dealing with the

fragmentation of the family that seemed to occur with the birth and subsequent hospitalization of a VLBW infant (Doll-Speck, Miller, & Rohrs, 1993).

A third important factor for maternal involvement with VLBW infants in the NICU is the relationship that develops between mothers and nurses. Initially there is often an imbalanced relationship because nurses have the technological expertise necessary for the infant's survival and thus become the main caregivers (Scharer & Brooks, 1994). It is only with time that mothers are able to assume more of a parenting role. Mothers of infants in NICUs have identified a number of sources of stress emanating form their relationship with nurses. Miscommunication and incomplete information about aspects of an infant's care are seen as the main stressors (Affonso et al., 1992). Mothers have reported that they have been discouraged from participating in their infant's care and felt that nurses often neglected to explain such things as the complexity of the technology (Kenner, 1990). Lack of support and inconsistent advice from nurses regarding breastfeeding were also identified as stressors (Jaeger, Lawson, & Filteau, 1997).

In a number of studies however, nurses have been identified as a major source of support for mothers, as well as a valued source of information about their infants (Abel-Boone, Dokecki, & Smith, 1989; Affleck, Tennen, & Rowe, 1991; Miles, Carlson, & Funk, 1996). These authors reported that mothers and fathers rated the support from nurses very highly. Support from nurses was rated higher than other health professionals. During the first week of the infant's

hospitalization the women in Miles, Carlson, and Funk's study, reported the nursing support was exceeded only by that of their partners.

Rationale and Problem Statement

Mothering an infant in a NICU environment has been found to be stressful. Stressors include an alteration in the mother's role and also the fragile appearance and behavior of the tiny sick infant. These stressors remain vivid for mothers throughout the hospitalization and are easily recalled even three years after the premature birth (Wereszczak, Miles, & Holditch-Davis, 1997). Distressing memories of the NICU experience can have serious consequences for mothers and may even negatively affect the maternal-child attachment process (Affleck, Tennen, Rowe, & Higgins, 1990). Given the continued evidence of the stressful nature of mothering in the NICU there are a number of reasons why it is timely to examine maternal involvement with VLBW infants in NICU environments.

Changes in the NICUs environments have been instituted to improve the outcome for infants and their parents. Over the past ten years clinicians and researchers have endorsed the components of individualized developmental care. This care incorporates modifications to the environment, the organization of care, care clustering, and improved paternal and maternal involvement (Als et al., 1986; 1994; Fleisher et al., 1995; Lotas & Walden, 1996). This changing environment of the NICU challenges researchers to investigate maternal involvement within that context.

Research designs used in previous studies may limit understanding of mothers in the NICU (Holditch-Davis & Miles, 1997). The use of observational techniques, surveys of charts, and questionnaires are not conducive to an in-depth analysis of the phenomena under study (Miles, 1989; Miles, Carlson, & Funk, 1996; Miles, Funk, & Kasper, 1991; Shields-Poe & Pinelli, 1997). Affleck, Tennen, Allen, and Gershman (1986) acknowledged that the cross sectional design of their study may have restricted the interpretation and understanding of the mothers' NICU memories. Qualitative work by Wereszczak, Miles, and Holditch-Davis (1997) uncovered aspects of maternal-staff misunderstandings in the NICU that had not been documented in any of their previous quantitative research (Brunssen & Miles, 1996; Miles, Carlson, & Funk, 1996; Miles, Funk, & Kasper, 1991).

The role of nurses in the NICU and their relationships with mothers of VLBW infants need to be reevaluated as there are a number of areas requiring additional information. Ambiguous relationships were inherent in the mother-nurse relationship studied by Miles and Frauman (1993). Nurses expressed concerns that their "caring" tasks might be misinterpreted by mothers as an attempt to mother the infants. Additionally, the ritualistic patterns of "older nurses" were viewed by mothers as an obstruction to their attempts to establish a routine with their infants. Stainton (1992) suggested that there are often mismatches between the mother's and nurse's perception of the maternal style of coping with the NICU. One of the limitations in research into nurse-parent

relationships is that they are sometimes only studied from the perspective of the nurse (Morse, 1991), yet both the nurse and the patient contribute to the degree of closeness in these relationships. Research is needed to delineate the components of a helpful relationship from the perspective of the patient. Nurses play a critical role in the establishment of a relationship that will enhance the mother's involvement with her infant. Since mothers do not usually know the NICU environment, the onus is on nurses to determine guidelines and directions that foster a successful relationship, but these guidelines need to take into account experiences of mothers.

Parents have frequently been left out of a number of decisions regarding their ill infant's care in the NICU, particularly regarding some of the ethical issues that inevitably arise (Tyson, 1995). Research in the area has focused on health professionals and their involvement (Lee, Penner, & Cox, 1991a; 1991b; Raines, 1993; 1996). When health professionals communicate the basis of decisions around the infant's condition and interventions required it is usually in euphemisms, vague statements, and half truths in an effort to protect parents (Guillemin & Holmstrom, 1983). Pinch and Spielman (1989a; 1989b; 1990; 1993; 1996) have examined parental perceptions of ethical decision making in the NICU. Parents tended to delegate responsibility of the medical care for their infants to health care professionals. They felt that treatment decisions were best made by those who had the best knowledge. However, they did express concern over their non-involvement in care for their infants in normal aspects of newborn

care; nutrition, cleanliness, and sleep. They experienced frustration because they felt that staff took over completely the care and parents felt like intruders in the NICU. Decisions around care and what has an impact on involvement in decision-making need to be considered when looking at maternal involvement in an NICU.

Research that has focused on parents' experiences in the NICU indicate some distinct gender differences in parental response to the birth of a VLBW infant. Several studies have shown that fathers are less distressed than mothers by a medically fragile infant (Affleck & Tennen, 1991; Levy-Shiff, Sharir, & Mogilner, 1989; Philipp, 1983). Significant gender differences in patterns of social support and coping have been documented (Affleck & Tennen, 1991; Graves & Ware, 1990; Hughes, McCollum, Sheftel, & Sanchez, 1994). Affleck and Tennen found mothers expressed their emotions, tried harder to mobilize social support, and used more escape-avoidance strategies while fathers had a greater inclination to minimize and control the problem. These findings were collaborated in a study by Hughes, McCollum, Sheftel, and Sanchez with the added insight of what might differentiate maternal and paternal coping. Neonatal morbidity was inversely related to the use of self-controlling coping by mothers. In contrast fathers of sicker infants used less self-controlling coping. These authors also found that fathers and mothers differed in their social support needs. Mothers identified the emotional support from their spouses as being the primary support they needed, while fathers identified the informational support they received from

the medical staff. A finding unanticipated by health professionals was that mothers and fathers were affected by different stressors (Graves & Ware, 1990).

Gender differences have been noted in parental visiting patterns in the NICU. Giacoia, Rutledge, and West (1985) found that although rural parents visited less often, made fewer phone calls, and earned less money than their urban counterparts, mothers in both groups visited more frequently than the fathers. Urban fathers identified the care of siblings as limiting their visiting options. Rural fathers cited demands of work, cost of the trip, and distance as the reasons for not visiting more often. Even within an urban population and despite visiting differences by income, insurance coverage, and car ownership, mothers visited their infants in the NICU more frequently than did the fathers (Brown, York, Jacobsen, Gennaro, Brooten, 1989).

With the changes in NICU environments, incomplete and conflicting findings of what helps or hinders maternal involvement, and gender differences noted in parental reaction and participation in the care of VLBW infants, it is timely to examine the woman's perspective of being a mother in an NICU. More research is needed in which mothers will identify interactions which enhance their involvement with their VLBW infants. This study addresses the role of the mother of a VLBW infant in the context of the NICU environment.

Purpose of the Study

The purpose of the study is to use grounded theory to examine the process of maternal involvement with their VLBW infants while the infants were in

the NICU. This investigation will develop a conceptual framework indicating what occurs among mothers with VLBW infants in the NICU in order to understand what may facilitate more efficacious maternal involvement in this context. Chapter one highlights the rationale for the study, the purpose, and the research questions. Chapter two will present a review of pertinent literature. Chapter three will give an overview of grounded theory as used in this study. Chapter four and five will include the findings and a discussion of the findings, respectively. The final chapter will contain the limitations of the study and some of the implications for nursing.

Research Questions

The research questions guiding the study are: What is the process of maternal involvement with their VLBW infants in an NICU? What conditions promote or hinder the mother's involvement? What may account for some of the differences in maternal involvement with their VLBW infants?

CHAPTER 2

LITERATURE REVIEW

There have been a number of studies that have attempted to examine parent's involvement or non involvement with aspects of their infant's care with their very low birth weight (VLBW) or other ill newborn infants while the infant was in a neonatal intensive care unit (NICU). The purpose of this chapter is to review the research in the area. Although the present study is limited to maternal involvement, research studies on parental involvement will be included, highlighting any findings related to mothers. The literature review is divided into the following sections that deal with factors that foster or inhibit maternal involvement with VLBW infants in the NICU environment: family visiting, decision making, nurse-mother relationship, and stressors in the NICU.

Family Visiting

Family-centered care has long been a philosophical orientation within acute care institutions. One of the clinical areas that has embraced this orientation has been maternal-child care. In the NICU grandparents and siblings are two categories of family members it was felt important to include for parental support, to prevent disruption in the family, and to integrate the new family member. However, research has demonstrated that the inclusion of these people in NICUs has not always been perceived as positive by NICU staff members and this has the potential to affect maternal involvement with their infants in the NICU.

In a U.S. study Blackburn and Lowen (1986) surveyed parents and grandparents to examine grandparents' visiting practices in an NICU. They found variation between the two groups in their perceptions of visiting restrictions. The grandparents were more likely to feel that the restrictions imposed were necessary for the infant's protection, while the parents, particularly mothers, were angry with the restrictions. The mothers felt that grandparents should be allowed greater involvement with their grandchildren and should be able to touch, caress, and hold the infant.

A later study conducted in Europe (deLeeuw, Cuttini, & Reid, 1993) focused on parent's involvement in the NICU from the perspective of staff. In 1990 a survey was sent to medical and nursing staff in 35 units from eleven European countries resulting in 1008 completed questionnaires. Findings indicated a strong agreement with unlimited parental visiting and involvement with their infant's care. Staff supported restricted visiting for grandparents and siblings. Seniority of staff was an important variable in that senior staff, defined as greater than seven years experience, showed a more negative attitude towards visiting and parental involvement.

Around the same period McHaffie (1991) concentrated on the visiting role of grandparents in the NICU. She administered a questionnaire to staff, parents, and grandparents from the seven largest neonatal units in Scotland. The results highlighted that physicians and nurses rated working with grandparents as the part of their work they least enjoyed. Reasons cited included: finding time to

speak to them, informational requirements, and grandparents wanting to know more than the staff felt the parents could handle. Parents were less satisfied than the grandparents with family visiting policies and often discouraged the grandparents from visiting because of restrictions on the latter group once in the NICU. Parents were also frustrated with rigidly applied rules that did not support non traditional families. They noted a fluctuation of rules yet a lack of flexibility. The parents also confirmed that grandparents are an important source of emotional support. Notwithstanding the dissatisfaction of parents, the majority of grandparents were tolerant of the restrictions and appreciative of the interactions they had with nursing and medical personnel.

Programs for sibling visiting have been developed that include educational and visiting components. One such program found that mothers identified that young siblings missed the new baby, wanted to visit more often, and asked many questions about the NICU environment and the sick infants (Doll-Speck, Miller, & Rohrs, 1993). The education program consisting of three, one hour sessions and a visit to the NICU for siblings aged three to eight which addressed the concerns of these children. Both mothers and fathers reported a high level of satisfaction with the program.

Sibling visitation in the NICU was the focus of a study by Meyer, Kennally, Zika-Beres, Cashore, and Oh (1996). They studied nurses' attitudes following the implementation of a sibling visitation program. The nurses generally rated the program positively. After the program they perceived less interference with

nursing care and nursery routines and had fewer concerns about infections. However, the visiting was restricted to children older than four years, limited to 10-15 minutes duration, and were scheduled for late afternoons.

Based on positive results of a structured facilitated child-visitation intervention (FCVI) in an adult intensive care unit setting (Nicholson et al., 1993), Montgomery, Kleiber, Nicholson, and Craft-Rosenburg (1997) evaluated such a program in a special care nursery in a tertiary care hospital. The intervention consisted of a previsit, visit, and postvisit evaluation. The benefits of the FCVI included the recognition of the importance of the sibling as a family member, decrease in emotional upset for the sibling, and support for the fathers and mothers at a time when the family is under considerable stress. Nurses appreciated the guidelines by which visiting could be structured and consistent from family to family.

A review of visiting practices in NICUs (Griffin, 1998) has found that the most common restrictions are: asking parents to leave during rounds, reports, and staff changes, allowing only two visitors at a time, limiting visiting to parents and grandparents, and constraints on sibling visits. She recommended more liberal visitation "guidelines" and more input on the part of parents as to whom they deemed should visit. Grandparents or relatives may not be the most important support for parents and guidelines need to reflect this; also flexibility in rules would be desirable. Parents also need the option of being more involved in rounds and reports so they can have greater involvement in discussions and

decisions involving their infants. These changes would be more in keeping with a family centered neonatal care philosophy.

Decision Making

A cornerstone of modern health care is the requirement of informed consent on the part of the patient for his or her care. VLBW infants are not autonomous beings with the ability to engage in informed consent, therefore, it is the parents in the absence of any extraordinary circumstances who are given the responsibility of decision-making on the part of the infants. However, many of the decisions regarding NICU care involve complex medical and ethical issues and occur at a time when parents may be very vulnerable. In the U.S. VLBW infants make up 7% of all infants yet 35% of the health care dollars spent on infants is spent on their care. Tyson (1995) recommends that national clinical trials be initiated involving parents in a formal evaluation of the technologies and therapies for VLBW infants. He contends that parental involvement in the decisions about the use of intensive care has been limited by health care professionals. Since the mid-eighties when technological breakthroughs in the NICU highlighted the need for greater attention to ethical issues, a number of researchers have focused their research on parental involvement, or lack of involvement, with these issues.

Much of what we know about parental involvement in ethical decision making in the NICU comes from the longitudinal research of Pinch and Spielman (1989a; 1989b; 1990; 1993; 1996). The first phase of the study used a phenomenological approach to assist the authors to identify themes relating to

the topic (Pinch & Spielman, 1989a; 1989b). In this phase the authors interviewed 32 families prior to their discharge asking them about two time periods; prior to admission and during the NICU care. Even though neonates spent on average 57 days in the NICU parental discussions focused on the period prior to admission. The parents seemed unaware of any ethical decisions that might have been made for their infants. This was contrary to the findings from the charts documenting multiple invasive procedures, viability concerns, and the iatrogenic effects of some of the treatment. Parents appeared to delegate the responsibility of the care of their infants to health professionals and expressed faith in God to guide the staff's decisions. They felt that treatment decisions were best made by physicians who had the necessary knowledge and whom they felt made treatment choices in the best interests of the infants. The parents considered the signing of consents for treatment as a perfunctory permission and even were grateful at this precarious time to have these ethical decisions made for them.

To investigate the themes identified in the first phase of the study and to continue her search for insight into parental perceptions of ethical decision making Pinch (1990) interviewed five families post discharge from the NICU. The parents were purposively selected in order to represent contrasting and varying characteristics of the NICU parent. Although the parents felt they lacked ownership of the critical decisions that had been made for their infants, there was no sense of animosity over this. Once again they reported that they accepted

health professionals as the decision makers and gave consent for procedures without question. They felt that the onerous task of decision making was out of their domain because of the technology involved. Even some parents with a health background did not understand some of the issues involved. Generally, parents did not perceive any controversy regarding issues of ethical decision making in the care of their infants.

In phase two of the longitudinal study Pinch and Spielman (1993) investigated parents' perceptions of ethical decision making six months post discharge from the NICU. Twenty eight of the original 32 families were identified and interviewed using a semi-structured interview guide. The phenomenon identified was one of an emerging ethical consciousness. Two thirds of the parents had children with either a serious sequel or questionable health status outcomes and were beginning to reexamine the NICU treatment decisions. They reflected on their lack of information and the complex medical jargon that they had found intimidating and difficult to interpret. They now wondered if the health professionals had acted in the best interests of their infants. The impact of the decisions that had been made in the NICU was now having a major impact on their family's functioning.

Twenty four of the original 32 families were recruited for phase three of the study and a semi-structured interview format used to elicit their concerns (Pinch & Spielman, 1996). Parents recalled their unquestioning acceptance of all treatments offered their children. Most parents wished that their NICU

experience had been different. They realized that at the time they lacked knowledge about the NICU in general and in specific information about the diagnosis and prognosis of their child. At this stage parents had dealt with the frustrations of the NICU experience that had been evident in phase two of the study and were more concerned with moving on and making the best of their lives. Their current concern was with the challenges of caring for a child with disabilities. Parents at this time emphasized the need for greater responsibility when using advanced technology in the rescue of infants. One father summarized the dissonance between health professionals' and parents' perspectives as "your miracle, my curse".

In contrast to the above findings, a study by Scholmann and Fister (1995) found that parents expressed a desire to have been more involved in the decisions relating to their infant's outcome from the beginning of hospitalization. They recalled their disappointment with the fact that doctors made decisions in treating their infants and only informed them after the fact. They recognized that their role in decision making was hampered by a lack of knowledge, limited choices, and fear of the responsibility of making ethical decisions.

Miya (1989) used a case study approach to delineate ethical quandaries in the NICU. The study centered on the issue of deciding whether or not to continue life support when an infant had significant neurological problems. She felt that well-informed parents, physicians, and other team members needed to be involved in the decision making process. Among team members she singled out

nurses, who had the most continuous, committed, and trusting relationships with parents and who are knowledgeable about the infant's condition, as critical in the decision. The Ethics Committee was also identified as beneficial in this situation. However, the final decision must focus on treating the infant with respect and dignity.

One study was conducted on mothers' values related to VLBW infants and their care (Raines, 1998). The researcher used a qualitative exploratory design to interview 14 mothers who had spent a minimum of three and a maximum of eleven days in the NICU. Four main themes or values were identified and labeled: being involved, technology for survival, the human factor, and attributes of the care giver. The value 'being involved" referred to the mother's feelings of being told about decisions after they were made rather than being included in the decision making process. Even though the mothers recognized that they did not have the technological expertise they felt they could be involved in decisions regarding hygiene, nutrition, and comforting. The second value reflected the mothers' thoughts on technology. They took comfort in the availability of technology and were reassured that this allowed their infants to survive. The third value was the human touch in the highly technical environment; something that surprised these mothers. Although they acknowledged the actions of other professions they consistently associated nurses with the human element. The fourth value singled out competence and caring as the highest ranked care giver attributes.

A study in Newfoundland, examined the attitudes, perceptions, and values of parents, nurses, and pediatricians regarding the care of VLBW infants (Lee, Penner, & Cox, 1991a). This quantitative study utilized a different questionnaire for parents and health care providers for data collection on treatment decisions. Even though nurses and pediatricians considered the attitudes of the parents as the most important indicator for their decisions, there were varying attitudes around saving an infant regardless of outcome. The majority of parents, 80%, felt all attempts should be made, nurses held an opposite view, and pediatricians were evenly divided on the issue. Differences were also found as to who should make the final decision for treatments of VLBW infants. Nurses and pediatricians were in support of pediatricians being the final decision makers, but parents overwhelmingly opposed this and felt they ought to have the final say.

Using the information from the previous study, Lee, Penner, and Cox (1991b) analyzed the impact of a VLBW infants on the family and the relationship to parental attitudes. The positive parental attitudes toward saving such an infant were attributed to the parent's willingness to accept any outcomes for their child and to take any chances on the possibility that the child would be normal. Interestingly, there was a difference in the responses of mothers and fathers toward saving a potentially handicapped child. Mothers were less inclined to save the child than fathers.

In collaboration with other parents, Harrison (1992; 1993) provided benchmark criterion for the participation of parents in the NICU with the "Principles for Family Centered Neonatal Care". Honest and open communication between parents and professionals provides the basis of this relationship. The principles promote parental involvement in all aspects of neonatal care: treatment options, policies, research, and the development of an appropriate NICU environment. They acknowledge the role of fully informed parents in choosing treatment options for their infants in medical situations involving high mortality and morbidity.

Nurse-Mother Relationship

Nurses can play a key role in promoting or hindering parental involvement with their VLBW infants in the NICU (Beaumont, 1997; Dawson, 1994; Hurst, 1993; & Maroney, 1994). The growing relationship between nurses and mothers during the hospitalization of the sick neonate was explored by Scharer and Brooks (1994). In their study, a core category emerged from the interpretation of the data entitled "the transfer of care". This was the process where the responsibility for the care of the infant gradually shifted from the nurse to the mother. Conflicts during the process were identified which warrant a careful examination by nurses of the mother-nurse relationship. Mothers often felt in a competitive or conflicting relationship with the nurse caring for the baby. Additionally feelings of jealously were often experienced over the nurse's ability to provide care and the nurse's knowledge of the baby's needs. Despite these

difficulties, most mothers reflected on the competence and caring nature of the primary nurses. Feelings of empowerment from the nurses strengthened the mothers desire to learn and perform the care for their infants. Findings from this study imply that nurses must strive to interpret the mothers' cues in order to minimize a potentially competitive or conflictual aspect of their relationship.

Stainton (1992) utilized a phenomenological approach to investigate the mothers' subjective experiences in high-risk perinatal situations. The data, collected from 27 participants, revealed "mismatches in caring" between the perceptions of the nurses and the mothers. The mothers focused on possibilities of positive outcomes regardless of the seriousness of the situation while the caregivers focused on potential or actual problems. The nurses, preoccupied with problems and problem development, misinterpreted the mothers' responses. They felt the mothers were not acknowledging the seriousness of the infant's condition. The researcher referred to the different sources of knowledge that guided the reasoning for both participants. The mothers gained their knowledge of the baby from a subjective stance, the inside; while others, from an objective view, the outside. These dysynchronous goals of caring lead to the mothers being labeled as denying and the caregivers as worrying.

Similar to the Stainton (1992) study, Miles and Frauman (1993) uncovered barriers to maternal involvement with their infants in the NICU. They used a comparative analysis technique to examine the nurse-parent relationship from data collected from 15 mothers of medically fragile infants and 15 nurses working

in units caring for the infants. They found that initially the mothers felt they were unequal partners in the care of their infants. Although mothers were assumed to have an important role, their attempts to implement their roles were fraught with barriers. Most caregiving tasks required the permission of the nurse who seemed to be distrustful of the mother's endeavors. Thorne and Robinson (1989) also found discrepancies in the parent-caregiver relationship. They reported three stages of involvement; naive trust, disenchantment, and guarded alliance. Families initially felt that caregivers had the same goals and perspectives as themselves. Realization of the differences resulted in parents reconstructing more realistic expectations of the providers.

An ethnographic study on the perceptions of the communication proceedings between parents and staff in the NICU identified the critical roles of nurses in this process (Able-Boone, Dokecki, & Smith, 1989). Parents identified nurses as the "facilitators of communication" between the parents and the health care team. The nurses were described as being "person-orientated" meaning they considered the child in the context of the family. The baby's primary nurse was identified by the parents as being their main source of information about their child.

The important role of nurses in helping parents handle difficult situations in the NICU was confirmed by Miles, Carlson, and Funk's study (1996). These researchers accessed the support network of parents at one week after the admission of their baby (T1) and one week later (T2). At T1 fathers identified

NICU nurses as providing the most support. The mother rated the baby's father as the greatest source of source at T1 and T2, followed closely by support of the NICU nurses.

A prospective study of mothers' active remembrances of NICU was done by Affleck, Tennen, Rowe, and Higgins (1990). Six months after discharge, 94 mothers described their memories. Mothers who described painful reminders of this crisis were often those who had difficulties in their relationships with nursing staff. These mothers had problems negotiating a partnership in their infant's care and in obtaining information about the infant's treatment. Mothers who reported pleasurable recollections remembered having greater control over their child's recovery, being supported by family and having received excellent neonatal care.

A longitudinal study of NICU maternal experiences revealed that at a year post discharge the mothers' memories of the NICU remained fresh in their minds (Hamelin, Saydak, & Bramadat, 1997). The mothers attributed their lack of personal knowledge of the infant to their initial contacts with the infant in the NICU. They felt jealous that the nurses were doing all the tasks for their babies and were "taking over the mothering role".

Nursing Support Strategies

The role of nurses in providing tours of the NICU has been recommended as beneficial for high risk parents (Montgomery, 1989; McKim, 1993). An evaluation of NICU tours was reported by Griffin, Kavanaugh, Soto, and White (1997). The parents recommended that the tour should be available for all high

risk parents and should be arranged to be done simultaneously with other hospital appointments. The benefits included decreasing their fears of NICU, inspiring hope for their baby's survival, and providing comfort in the knowledge that the nurses and physicians were giving such quality care. The parents suggested that the tour should include more information on the parental role in the NICU: the sibling role, breastfeeding support, and other interventions that would enhance the parental role. The parents also recommended that the tour be offered to other perinatal staff so that they could support parents and encourage parents to participate in the tour.

Nurses have also been involved in developing parent-to-parent support groups in the NICU. One of these programs promotes the use of veteran parents to help novice parents adjust to the NICU environment (Lindsay et al., 1993; Roman et al., 1995). This differs from the use of support groups that have met with varying degrees of success. Mothers found support groups to be time consuming; taking them away from their sick infants. Sharing similar experiences, a common goal of groups, has been reported as being terrifying and stressful for some parents (Stauber & Mahan, 1987). The fundamental support processes with the parent-to-parent support was to provide emotional support, informational support, and maternal role support. The volunteer veteran parents are screened by the nurse co-ordinator of the program and provided with training on how to be a support parent. An evaluation of the program was done using multiple instruments to measure self esteem, mood status, family functioning,

maternal-infant interaction, and quality of the home environment (Roman et al., 1995). Significant differences were found on the mood states scale between groups. Mothers in the intervention group experienced lower levels of anxiety, depression, fatigue, and confusion at four months post discharge. At twelve months, participant mothers had better maternal-infant relationships, and more nurturing home environments. Other studies have reported that the most helpful thing about a parent-to-parent support program has been the comfort in talking with someone who has lived the same experience; the experience of the NICU (Jarrett, 1996a; 1996b).

Parenting can be a major challenge especially if the baby is preterm and the parents are young, poor, and lacking parental skills. Improving parenting skills has been shown to improve infant development and increase parent's confidence in dealing with day to day health matters for their infants (Gennaro, 1991). Premature babies, more disorganized in their behavior, may not provide parents with positive reinforcement (Gennaro, Zukowsy, Brooten, Lowell, & Visco, 1990). Nurses need to make parents aware of the behavioral cues of their babies and support them as they provide normal baby care such as bathing and feeding. Parents should be made aware of the growth and development issues and the importance of a stimulating environment.

The commitment of nurses is essential in promoting, supporting, and providing guidance for developmental care components (Affonso, Bosque, Wahlberg, & Brady, 1993; Strauch, Brandt, & Edwards-Beckett, 1993). The

feasibility, safety, and emotional reactions of mothers to kangaroo care, the placing of the infant in a vertical position between the mothers' breasts in skin to skin contact, was studied in a tertiary care NICU (Affonso, Bosque, Wahlberg, & Brady, 1993). Over a three week period, four hours per day were devoted to Kangaroo Care by the study mothers. During the first week, the mothers were preoccupied with the experiences of labor and delivery and expressed some anxiety about holding the infant in this manner. At the end of the second week, mothers experienced a sense of mastery of the infant caregiving skills and knowledge of their babies. At the completion of the study period, the mothers expressed feelings of confidence in their caretaking role, pride in their accomplishments, and a firm establishment of their mothering roles.

The literature suggests nurses support of mothers can be enhanced by their involvement in breastfeeding initiatives (Wereszczak, Miles, & Holditch-Davis, 1997). Breastmilk, which can supply immunological and growth-promoting benefits to the preterm infant, also provides the mother with the opportunity of doing something worthwhile for her baby. Jaeger, Lawson, and Filteau (1997) examined the quality of support for mothers wishing to breast feed their preterm infants. Although generally the mothers felt the support of nurses to be good, initial breast feeding endeavors by the mothers led to frustrations. Conflicting advice from the nursing staff left the mother overwhelmed. One mother stated "the baby mother relationship is put a very poor second to the baby-scientific care" (p. 733). Nurses must be aware of barriers which preterm mothers in the

NICU perceive as barriers to breastfeeding. These include lack of privacy, the high stress and noise level of the NICU, bottle feeding before initiation of breast feeding, and the fragility and medical condition of the infant (Furman, Minich, & Hack, 1998). Strengthening informal support systems has been advocated as a strategy to improve the initiation and duration of breastfeeding. The male partner has been identified as an important source of support for mothers of preterm babies (Miles, Carlson, & Funk, 1996). Efforts must be made to involve the male partners in policies, programs, and educational efforts aimed at supporting breastfeeding (Raj & Plichta, 1998).

Stressors in the NICU

Research has consistently identified stressors that parents of VLBW infants encounter, such as the unexpected birth, concerns about a sick infant, uncertainty about the outcome, and admission to the NICU. Findings indicate that these factors have the potential to interfere with maternal bonding and may result in problems after discharge. Problems of inadequate parenting, child neglect, failure to thrive, and breakdown of the family unit have been reported (Consolvo, 1986; Perehudoff, 1990; Steele, 1987).

Sources of Stress

A number of researchers have examined the sources of stress in the NICU environment. Miles (1989) administered the Parental Stress Scale: NICU (PSS: NICU) and a personal situational questionnaire to 53 parents prior to their infant's transfer or discharge from the NICU. The highest ranked stressor was the

infant's behavior and appearance. The most stressful aspects of the infant's appearance was when he/she stopped breathing, turned blue or pale, looked limp or weak, or had a sad look. The second highest stressor was parental role alterations like long separations, not being able to help, unable to hold the infant or protect them from pain. Only a moderate degree of stress was caused by staff-parent relationships. Inadequate communication with staff left parents feeling they were not told everything. Staff who were perceived as cold and insensitive caused distress to the parents. The physical aspects of the unit, the sights and sounds, were found to be the least stressful for the parents. However, situations that could mean problems for the baby, malfunctioning equipment, and sudden alarming of the monitors were stressful. Content validity, construct validity, and internal consistency were established for the PSS:NICU scale supporting its use as a research stool to evaluate stressors experienced by parents with infants in NICU (Miles, Funk, & Carlson, 1993).

The sources of parental stress identified by Miles (1989) were verified by Miles, Funk, and Kasper (1992) in a large, more representative sample of parents. Included in the study were 79 mothers and 43 fathers. In contrast to Miles's study they found that alterations in parental role caused the greatest stress for the parents while the appearance of the fragile sick infant was the second highest cause. They determined the state and trait anxiety levels of parents as it related to the NICU environment and significant correlations were established between environmental stress scores and both trait and state anxiety

scores. The data collected during the first week of the infant's hospitalization, showed trait anxiety scores that were comparable to those of young adults tested under high stress situations. Health care professionals need to be aware that the anxiety level of parents may interfere with their ability to hear explanations, make decisions, and be involved with their children. These authors advise that the stress related to the NICU can be reduced by providing information, normalization, and support. The most frequently mentioned stressors in the two previous studies was related to the infant; the infant health status, and the infant's appearance.

The maternal perception of severity of the infant's illness may or may not be related to the actual severity. To determine if a relationship existed between perception of severity, infant's appearance, and anxiety in mothers, a study was done using the Neonatal Morbidity Scale and the State-Trait Inventory (Catlett, Miles, & Holditch-Davis, 1994). The findings indicated that maternal perceptions of the severity of the child's illness were initially related to the birth weight on admission but within a few days it was determined by the actual severity of the illness. Mothers perceived their children as being more ill than they actually were on admission. The researchers felt this discrepancy may be due to the emotional impact of birth, the NICU environment, the appearance of the baby, as well as, communication with the NICU personnel. An inverse relationship existed between the mother's perception of severity of illness and their anxiety level.

Previous research on maternal stress responses to the preterm infants found that major concerns centered on the infant's survival and long term care rather than on the mother's disappointment, resentment, or other symptoms (Pederson, Bento, Chance, Evans, & Fox, 1987). These researchers found that the sources of support for the mothers included fathers, parents, and for church members, churches were a major source of strength.

A comparative study of parental stressors in the NICU and PICU found that the subscale with the highest score for both groups was parental role alternation followed by the infants' behaviors and appearance (Seideman et al., 1997). In the NICU, being separated from the baby, feeling helpless about how to help the baby, and being unable to assist the baby in pain contributed to the highest stressor scores. When staff behaviors were assessed, NICU parents found that staff interventions relating to assisting them in their parenting roles were less helpful than those for the PICU parents. Good physical and technical care was rated the highest by mothers and fathers both in NICU and PICU. The most helpful staff behaviors for NICU parents were being able to phone the unit at any time, having explanations about equipment, having questions answered honestly, being informed about the child's progress, and being provided with hope.

Gender Differences

Gender-related responses to stress in the NICU have been identified. While mothers have reported they receive less support than they need, fathers

indicated they received sufficient support (Blackburn & Lowen, 1986; Perehudoff, 1990). Miles, Funk, and Kasper (1991) investigated the differences in the stress responses among mothers and fathers at two time intervals; within one week of their infant's admission to NICU (T1), and one week later (T2). Both fathers and mothers identified parental role alteration as the most significant stressor, however, mothers' scores were markedly higher than fathers at T1 and T2. Maternal and paternal scores decreased significantly from T1 to T2. Stress related to the infant's appearance was rated as the second highest stressor for both parents, with no difference in the perception of stress between parents. Parents were similar in their rating of the stress of sights and sounds of the NICU. Levels of parental uncertainty were measured on four dimensions: ambiguity, lack of clarity, lack of information, and unpredictability. Both parents had higher scores for all measures at T1 with the greatest level of uncertainty being in the area of unpredictability. Mothers reported greater uncertainty than fathers in this area. Unpredictability, or the inability to predict the child's outcome, remained a constant problem for both parents.

Although extensive research has been done using the PSS:NICU, few studies have correlated levels of parental stress with specific variables. Shields-Poe and Pinelli (1997) used a multiple regression model to explore how variables from the PSS:NICU and state trait anxiety inventory scores contributed to parental stress. Mothers had higher stress scores than fathers on two subscales: interaction with the baby, and sights and sounds. Most of the variance in the

model was related to trait anxiety and perceived morbidity. Perceived morbidity was the most powerful variable associated with stress scores. It modified the parents' interactions with their infants and in certain situations, their interactions with hospital staff. Stress subscales were different for the mothers and fathers. For mothers, the subscale score variables were those related to the interactions with the baby. They included trait anxiety, where she first saw the baby, and the perceived morbidity of the baby. For the fathers, the variables were associated with sights and sounds, staff behavior, and communications. Included were trait anxiety, time to the first visit, speaking with the social worker, time of the interview, whether or not the pregnancy was wanted, and the perceived morbidity of the baby. Knowledge of the impact of perceived morbidity had significant implications for staff. It demonstrated to them the importance of coveying clear, frequent explanations to the parents.

Long Term Effects

Factors that contribute to maternal stress were found to change overtime (Affonso et al., 1992). These researchers found that the highest level of stress in the first 96 hours in the NICU was due to maternal separation. Factors causing separation included inadequate transportation, child care, and economic resources. In addition to physical separation, psychological separation was also identified. "Holding my baby" was found as distressing as "not holding my baby" due to fears about the physiological instability of the baby in the latter group. Mother's stress was intensified by their reflection on their unpreparedness for

labor and delivery. Emotional stress, present throughout the study period, was the most frequent and intensive negative stressor during the second assessment. Mothers reported disappointment and guilt over the birth of a premature baby. They discussed their feelings of being helpless, crying a lot, and being out of control. Communication with nurses was a major concern at this time. Mothers felt that nurses gave incomplete and inconsistent information and were often unaware of the needs of the parents. At the third and fourth assessments, maternal stress shifted to mothering concerns and financial worries in relation to the mother's preparation for discharge and her perceived inability to care for her child after discharge.

In a longitudinal study of mothers' remembrances of the NICU, the impact of positive and negative memories were evaluated (Affleck, Tennen, Rowe, & Higgins, 1990). The majority of mothers believed that memories were helpful and reminded them of the progress their child had made, how precious the child was, their personal gains, and reminded them of their child's special needs. Mothers who were experiencing painful reminders of the NICU at discharge were more likely to have had problems with staff, sicker children, and were currently feeling less attached to the child. Mothers encountering pleasurable reminders were more likely to perceive more control over their infant's recovery and have construed a purpose in the crisis. The most common painful memories were the severity of the child's condition, how hard it had been to cope with the experience, and difficulties in relationships with NICU personnel. Pleasurable

memories included the recollection of support from family, friends, and staff, the excellent medical assistance, and how precious their child was because of the miracle of survival.

Maternal feelings and interactional patterns with their preterm babies were studied at two times; within ten days of birth (T1) and again at three to five weeks after birth (T2), by Oehler, Hannan, and Catlett (1993). Changes occurred over time. Feelings of anger increased from T1 to T2, although no reason for the anger was documented in the study results. At T2 a high percentage of the mothers continued to report feelings of being scared or nervous. At the second interview, mothers expressed more confidence in being able to distinguish and respond to behavior cues from their babies. The most frequent type of interactions mothers identified were talking to and touching their infants. The infants responded through body activity, eye opening, and orientation. However, half of the mothers were unable to interpret their infant's cues. It has been noted that mothers often fail to detect and understand the cues of VLBW infants that results in overstimulation of the infant (Field, 1977).

Comparisons of the level of maternal anxiety in mothers of term and preterm infants has produced conflicting results (Choi, 1973; Scheiner, Sexton, Rockwood, Sullivan, & Davis, 1985). As a contribution to this research area, Gennaro (1988) conducted a longitudinal study comparing the anxiety and depression scores of mothers of term and preterm infants. Measures were done at one week postpartum and at weekly intervals for six weeks. There was a high

attrition rate with 41 pairs completing the first testing and 16 (preterm) mothers and 10 (full term) mothers completing the seven weeks. During the first week, there was a statistically significant difference between the level of anxiety and depression between the mothers of the preterm and term babies. The higher level of anxiety and depression for preterm remained constant regardless of the severity of illness of the child. During weeks 2 to 7, both groups of mothers experienced similar responses for anxiety and depression. At week four (term) mothers and week five (preterm) mothers showed a rise in anxiety scores. The author suggested that this might be due to the fact that the baby "honeymoon" was over and reality had set in. Other research has focused on preterm mother's level of anxiety and depression at discharge and at nine months post discharge (Brooten et al., 1988). This quantitative study used the Multiple Affect Adjective Checklist to measure maternal anxiety, depression, and hostility of 47 mothers of infants with birth weights of less than 1,500 grams. Preterm mothers were more anxious and depressed before discharge than at nine months post discharge and mothers whose babies stayed in hospital longer than 51 days were significantly less depressed and anxious at discharge.

The long term influences of prematurity and related NICU stressors on the parenting of three year old prematurely born infants were evaluated (Miles & Holditch-Davis, 1995; Miles, Holditch-Davis, & Shepherd, 1998). Utilizing data from questionnaires and taped interviews, these researchers concluded that mothers used a unique parenting style that they labeled, compensatory parenting.

In an attempt to compensate for the neonatal experiences the mothers provided special experiences for their children. Alterations were found in four aspects of parenting: protection, stimulation, attention, and limit setting. The difficulties the mothers experienced in limit setting for the children appeared to be related to residual memories of the NICU experiences including guilt feelings because the mothers felt they were unable to spare their infants pain and suffering.

Further research on the long term memories of the NICU was reported by Wereszczak, Miles, and Holditch-Davis (1997). A grounded theory approach was used to evaluate the mothers' recall of experiences and responses during their infant's NICU hospitalization. Confirming previous research on stressors, they found that even after three years, mothers' memories of the appearance of the infant and alterations in their parenting role remained vivid. Two additional sources of stress were reported by these mothers: staff communication patterns and prenatal stressors. Mothers reported difficulty in getting consistent information in an understandable manner and being giving negative information more readily than positive information. Additionally, 46% of mothers had concerns regarding the care of their infants, the attitudes of staff, and behaviors that the mothers felt were neglectful. The researchers suggested that these new findings might be related either to the fact that mothers who were no longer dependent on the NICU staff felt more freedom in expressing their concerns or that while their infants were in the NICU the mothers had a strong need to feel that the staff were competent and caring. The strategies mothers recalled as

being used to deal with the stress of NICU included downward comparison, searching for meaning in the crisis, and normalization.

Summary

The literature review on visiting, decision making, nurse-mother relationship, and stressors in the NICU has revealed gaps in relation to the mother's involvement. Parents and grandparents continue to encounter inconsistencies in the visiting policies that often reflect a lack of consideration of individual family needs. This review indicated that the visiting policies in the NICU are still evolving and there is a need to have mothers and fathers assist in identifying the guidelines on visiting which they consider important. The involvement of mothers in decision making in the NICU has been found to vary considerably. Mothers stressed by the abrupt termination of their pregnancies have put their trust in the medical profession to make decisions. Yet, it has been shown that neonatologists and nurses have varying opinions on the resuscitation efforts of the VLBW infants (Dunham, MacDonald, & Singhal 1994). Research indicates a need to study the involvement of mothers of VLBW infants in the NICU in order to have a clearer understanding of their active participation in the decision making process.

Research has identified the key role that nurses play in the NICU setting. A seamless integration of professional expertise with maternal care would set the stage for optimal outcomes. However, "mismatches" have occurred in the

mother-nurse relationship that emphasize the need to broaden our knowledge to include that embedded in the subjective stance of the mother (Stainton, 1992).

It has also been established that the birth and subsequent hospitalization of a VLBW infants constitutes major stress for mothers and fathers. This stress remains vivid for the parents during the hospitalization, post discharge, and even after three years. The impact of the stress can cause a crisis in the lives of the parents that can have significant effects on the bonding or attachment to the infant. There is a need to explore further with the mothers those issues that potentiate stress in order to gain further insight into stress management. This literature review substantiates the need to investigate further the maternal subjective experiences in the NICU in order to provide caregivers with a clearer understanding of practices that would enhance neonatal family centered care.

CHAPTER 3

METHOD

Research Design

In this qualitative study, a grounded theory research approach as outlined by Glaser and Strauss (1967) and further described by Chenitz and Swanson (1986) was used to guide the researcher in conducting the investigation into the process of maternal involvement with their very low birth weight (VLBW) babies in the Neonatal Intensive Care Unit (NICU). Grounded theory is the collection and analysis of qualitative data for the purpose of generating theories that further the understanding of social and psychological phenomena (Chenitz & Swanson, 1986). Data collection and theory generation are viewed as two parts of the same process. The approach is useful in illuminating phenomena that have not been subject to much formal scrutiny.

Symbolic interactionism, the theoretical framework of grounded theory, is an approach to the study of human behavior (Chenitz & Swanson, 1986). It focuses on the meaning people ascribe to events in everyday life. Symbolic interactionism is concerned with the study of "the inner or experiential aspects of human behavior, that is, how people define events or reality and how they act in relation to their beliefs" (Chenitz & Swanson, 1986, p.4). According to Blumer (1969), human behavior results from a person's interpretation of the meanings of things derived from social interactions. He stated that a person does not merely respond automatically to situations but is "an acting organism who has to cope

with and handle such factors and who, in so doing has to forge and direct his line of action" (p. 55). The premises of symbolic interaction serve as the theoretical underpinnings of grounded theory.

Grounded theory, focusing on human behavior and interaction, studies a phenomenon in its naturalistic setting. Through data analysis, the aim is to discover dominant themes, show the linkages between these themes, and generate conceptual frameworks for emerging theory (Corbin, 1986). The primary strategies utilized in grounded theory are constant comparative analysis, concept indicator model, and the use of theoretical sampling. Constant comparative analysis refers to the continuous examination of the data from a variety of angles in an effort to achieve theoretical sensitivity, abstract conceptualization, then integration, and reduction of the data. Data collection, examination, coding, categorizing, conceptualizing, and writing occur simultaneously. The data collection continues until saturation of the categories of the newly generated theory is complete in that no new knowledge is forth coming to change the category's name (Chenitz & Swanson, 1986).

Central to grounded theory is the concept indicator model. Glaser and Strauss (1967) suggest that indicators are those features of the data which point to or are indicative of a particular category whilst "a property is a conceptual aspect of element of a category" (p. 36). Identification of categories and their properties constitutes the initial analysis of the data and provides the link between data and theory.

The method used to select the sample in grounded theory is theoretical sampling, a type of purposive sampling. Initially, selection is based on the ability of the participants to illuminate aspects of the phenomena being studied. As more comprehensive categories surface, the sampling becomes more selective. The data is collected according to themes that arise from the analysis. It involves examining each category in light of incoming data to ensure that emerging categories are fully developed. Sampling continues until all the categories have been saturated by the major variables evolved from the data (Corbin, 1986).

Criteria for ensuring quality of the data in qualitative research include credibility and confirmability. Credibility, confidence in the truth of the data, can be enhanced by prolonged engagement and by using debriefing techniques (Lincoln & Guba, 1985). Prolonged engagement involves the investment of sufficient time in data collection in order to establish rapport with the participants. This trusting relationship promotes sincerity and avoids the pitfalls of misinformation. Debriefing techniques can include validating the findings with peers (research committee) and informants (Lincoln & Guba, 1985). The concept of confirmability, achieved through inquiry audits, establishes agreement about the relevancy or meaning of the data.

Participants

Twelve mothers participated in the study. They were chosen on the basis of meeting the inclusion criteria: (1) ability to communicate in English, (2) had a baby with a birth weight of less than 1500 grams, who required NICU care for a

minimum of 21 days and who had been discharged from the study hospital between June, 1997 and July, 1998, and (3) were willing and able to talk about their experiences. The researcher worked with the nurse co-ordinator to approach mothers who met the above criteria. In addition, because the nurse co-ordinator had knowledge of these mothers and their experiences in the NICU she was able to assist the researcher to select participants with varied NICU experiences. Varied experiences helped to facilitate theoretical sampling.

The NICU is the sole tertiary level Unit providing neonatal intensive care to a provincial population of 550,000. The province reported 5008 births in 1998, 0.6% were less than 1500 grams. All babies requiring tertiary level care were transported from an outlying hospital. The majority of the babies were transported from a hospital within the City.

Of the twelve mothers, eight were first time mothers and four had a child living at home from a previous pregnancy. All mothers were living with the infants' fathers at the time of the study. The mothers lived varying distances from the hospital. Six mothers lived within the city and the remaining six lived distances from eighty miles to 450 miles from the City. Five of the six mothers who lived outside the City made a temporary home there while their babies were in the hospital. One mother commuted from her home to visit her baby on a biweekly basis. This trip would take approximately four hours.

There were 14 babies in the study, ten singletons and two twins. The gestational age for the babies ranged from 25 to 31 weeks, and the length of

hospitalization in the NICU from 27 days to 72 days. The birth weight for the babies ranged from 532 grams to 1294 grams. The time from the infant's discharge to the maternal interview ranged from 2 to 15 months, the average being 7.5 months.

Procedure

The Program Co-ordinator of the Provincial Perinatal Program agreed to identify babies and their mothers who met the inclusion criteria and to act as the intermediary in making contact with the mothers. A telephone script was used by the Program Co-ordinator to inform the mothers about the study and to seek permission for the researcher to make contact with the participants (Appendix A).

Mothers who agreed to participate were contacted by the researcher and given an overview of the study and the methodology (Appendix B). A convenient time and place were mutually decided upon for the researcher to meet with each participant and conduct the interview. The written permission of the mother was obtained to tape the interview.

The Setting

Participants were asked to select a setting for the interview that would be most convenient for them. It was felt that the participants would be more comfortable in a setting that had been chosen by them. Ten participants chose to be interviewed in their own homes, one chose to be interviewed at the hospital, and one was interviewed in the researcher's home. In all cases, emphasis was placed on having a quiet setting where there would be no interruption. Using a

similar setting for the interviews provided consistency of conditions for data collection.

Data Collection

The interviews were conducted between September, 1998 to November, 1998. The data were collected using an unstructured interactive interview including if necessary, some semi-structured questions (Morse & Field, 1995). In an effort to ensure a comfortable relaxed atmosphere the researcher spent a little time before the interview discussing the baby's present status. The interview was begun with an open ended question and then as necessary, the guide for the interview was used (Appendix C). This guide consisted of statements to help keep the interview focused. In an effort to keep the conversation flowing, the researcher used the guide only as necessary. The interviews lasted forty-five to sixty minutes and were audiotaped. Tape recording the interviews facilitated a more accurate way of collecting the data. Probes such as, "ummm, and "yes", were used to encourage the participants to tell more about their experiences. Silences occurred that allowed participants to collect their thoughts. More directed interviewing was necessary as the study proceeded in order to substantiate the data.

At the completion of the interview the participants were asked their permission to make further contact if a second interview was necessary or if verification of the contents of the transcripts was required. No second interviews

were conducted. Data saturation occurred with the first interview. The tapes were transcribed in their entirety by a typist using a word processor.

Data Analysis

Data analysis began immediately after the taping the first interview. The researcher listened to the tapes and made notes immediately following the interview. The tapes were then transcribed verbatim. The researcher then listened to the tapes while reading the transcripts to ensure the exactness of the transcription. The transcripts were read line by line, the incidents or facts were underlined, and rewritten in the margin as substantive codes. Memos were written to capture the main ideas that were triggered by the substantive codes.

To deal with the large volume of data contained in the interviews, each interview was first divided into three phases of the NICU experience; going there, being there, and leaving there. In the first phase all references to the birth and preparation of the baby for transport to the NICU were included. In the second phase, being there, included; arriving in the NICU, settling in, and getting comfortable there. The third phase of the experience referred to leaving the NICU. All twelve interviews were separated into these phases.

Each phase was then scrutinized for the main concepts. Lists were made of codes which had a common theme. These lists were analyzed for similarities and differences and grouped into clusters. Each cluster was analyzed in depth, seeking variations and common contextual issues that appeared both within and

across the clusters. Several related concepts were grouped together to form a category. Early in the data analysis several categories were identified.

To facilitate the second phase of the analysis: building, densifying, and saturating the categories, the researcher entered a process of questioning the data. Through reflective thinking, discussion with experts in data analysis, and a literature review, attempts were made to ascertain the properties of the categories and to understand the context and conditions in which they occurred. The categories initially developed were verified and refined as data collection continued. Further theoretical saturation was sought with the addition of each new participant. Literature was reviewed in an ongoing fashion as new inferences from the data were made.

As new categories emerged some of the earlier categories were deleted or combined with other categories to give a richer meaning to the developing process. Linkages were developed between the categories in an effort to bring conceptual order to the data. The processes of data collection, coding, and data analysis were intertwined although they have been presented as occurring in an orderly fashion.

Credibility and Auditability

Credibility and auditability have been endorsed by Sandelowski (1986) as techniques to establish rigor in qualitative research. Creditability or the truth value of the emergent analysis was enhanced by the constant comparative method itself. In-depth concentration of the researcher on the simultaneous

collection and analysis of the data focused the research. The analysis was also repeatedly compared and linked with relevant research literature to identify and correct potential inadequate inferences.

Auditability refers to the ability of another researcher to follow the methods and conclusion of the original researcher (Sandelowski, 1986). In the current study, collegial input was sought to verify or debate analytic inferences. Meetings were held with members of the thesis committee during the data analysis phase and the transcribed data were discussed. Consensus was obtained from members of the committee regarding the interpretation of the categories.

Ethical Considerations

Prior to commencing this study, permission was obtained from the Human Investigation Committee (HIC), Memorial University of Newfoundland (Appendix D). In addition, a letter of support for the study was received from the administrative representative from the Health Care Corporation of St. John's (Appendix E). Members of the Child Health Program were informed verbally and formally about the proposed research (Appendix F, G, H).

The Program Co-ordinator of the Provincial Perinatal Program contacted the participants, informed them of the study, and obtained their permission for the researcher to contact them. The participants were contacted by the researcher and given an overview of the study and their permission was obtained to audiotape the interview.

Immediately prior to the initial interview with the participants, the researcher reviewed the consent that outlined the risks, the benefits and the voluntary nature of participation (Appendix I). The risk associated with the study was the possibility of the participant becoming upset when they were asked to recall memories of the NICU. This would remind them of when their babies were critically ill and in danger of dying. If a mother became upset during the interview, the tape was stopped, the participant was given time to recover, and her permission was obtained to continue with the interview. The discomfort or inconvenience of the study would be the time it took to do the interview. The benefit for the participant would be the cathartic value involving the opportunity to discuss the NICU setting with an interested listener. The participants were given time to read and ask for any clarifications concerning the consent. Two copies of the consent were obtained, one for the participant, and one for the researcher. The name and phone number of the researcher was made available to the participant. Participants were made aware of the voluntary nature of the study and that they could withdraw from the study at any time.

The researcher confirmed verbally and in writing, the permission to tape the interview. The mother was assured that her anonymity would be protected by using code names instead of real names on the interview data and was guaranteed that all identifying information would be kept confidential. The typist who transcribed the tapes signed an agreement to preserve the confidentiality of the tapes. This person was recommended by the thesis supervisor and has done

transcriptions for a number of qualitative research projects. The data collected on audio tapes and the transcriptions were kept confidential. The names of the mothers and the corresponding tapes were known only to the researcher.

CHAPTER 4

FINDINGS

The process of maternal involvement with a very low birth weight (VLBW) infant in the Neonatal Intensive Care Unit (NICU) begins with the birth and subsequent transfer to the NICU. It involves a series of stages whereby the mother is able to gradually take over the maternal role as would have occurred if she had had a healthy newborn who did not require extensive hospitalization. Central to maternal involvement is its focus on the evolving process of maternal role adaptation in the NICU. It involves the mothers overcoming the emotional and physical barriers of this unfamiliar environment and being able to establish her role as a mother. Becoming a Mother in the NICU is, therefore, the core variable and involves three overlapping stages: *caring from the margins, shifting the balance,* and *making progress* (Figure 1).

Stage 1: Caring From the Margins

The birth of a VLBW infant abruptly ends a woman's pregnancy. It forces her to face the psychological task of caring for an infant before the anticipated time for such an event. This places the mother in a vulnerable position in a role for which she may be unprepared and unfamiliar. She has a critically ill infant whom she cannot provide care for because of the infant's condition and a dependency on "high tech" care. Caring from the margins describes this process which occurs following delivery. It is the time when the normal tasks of becoming a mother have to be put on hold as the reality of having

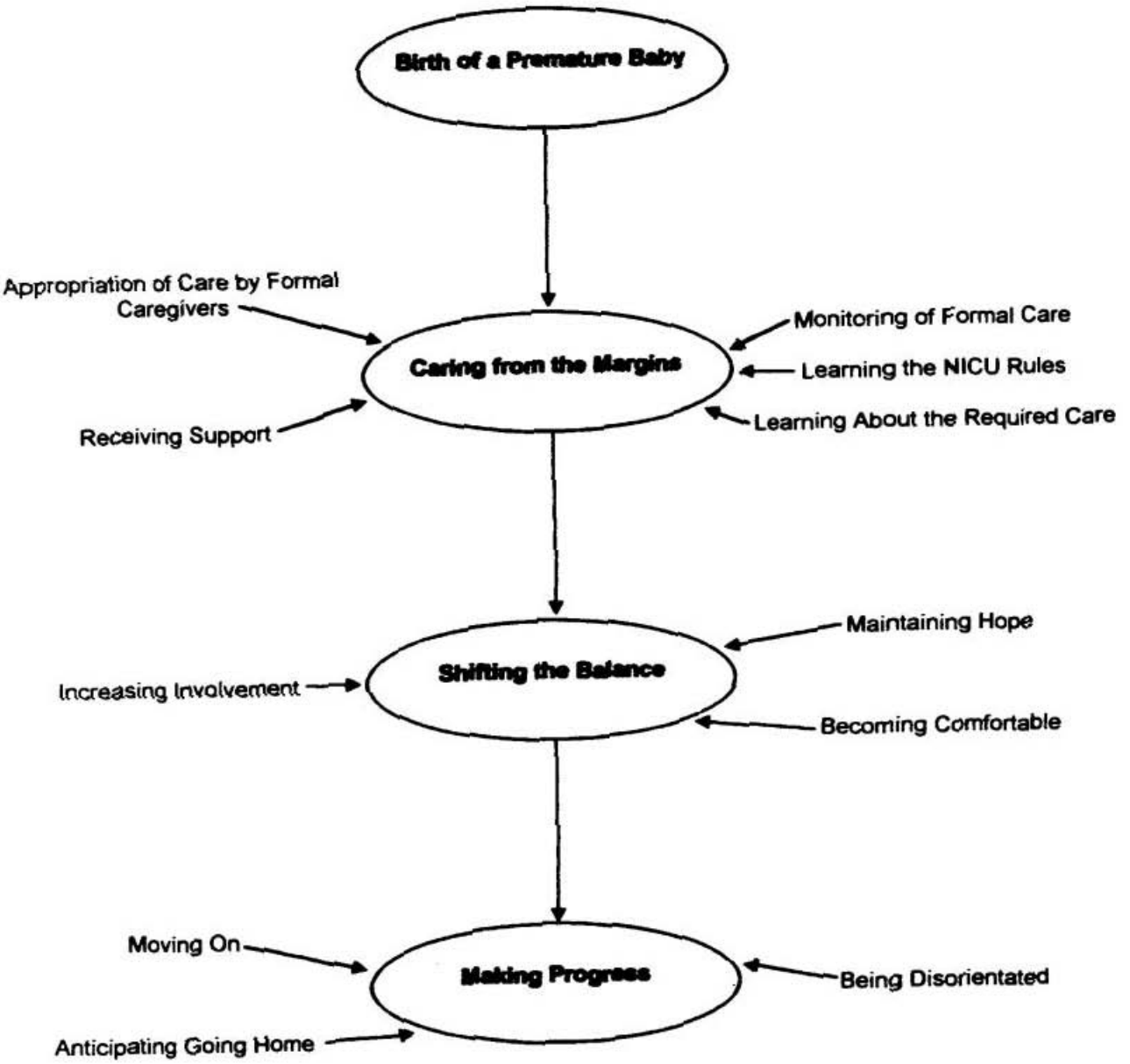

Figure 1: Becoming a Mother in the NICU

a critically ill infant predominate. Her baby's future is uncertain and she has to entrust the care of her baby to the medical team. She becomes a more peripheral caregiver in the physical care of her premature infant. She may also be distanced emotionally because of the unstable state of her infant. This stage includes five substages: (a) appropriation of care by formal caregivers, (b) monitoring of formal care, (c) receiving support, (d) learning the NICU rules and (e) learning about the required care.

Appropriation of Care by Formal Caregivers

During this substage the total care of the infant is taken over by formal caregivers. They take possession of the infant and his/her care in order to improve the chance of survival. The birth of a VLBW infant differed significantly from the birth of a normal healthy baby. For the mothers, the joyous occasion was replaced by feelings of uncertainty and a sense of grieving over the potential loss of the infant. The mothers initially experienced a state of anomie, unsure of the outcome for their babies, distressed by their inability to provide mothering and the physical separation from their babies. Mothers reflected on the possibility of the outcome for their babies.

> The chance of survival was slim to none
> It was just one of those chances, there was a good chance he wouldn't survive
> I think it was a 70% chance that he could and then again he might not. It was just touch and go. They didn't know at this point.

Following delivery, there was a sense of urgency as the babies were immediately transported to the stabilization unit. A fleeting glance at the baby established that the baby was really small and fragile. This increased the mother's anxiety as she had never seen a baby so small. At this point the mothers described they "moved to the side" and allowed the medical team to take over the care. It was obviously a critical situation. The specialized team had been called, the activity around the baby intensified. Procedures were being done, the baby was hooked up to an array of strange machinery. They were preparing to take the baby from the birth hospital to the tertiary care center. The clergy was called in to do an to an emergency baptism. For some this confirmed the mother's fear of her baby dying. The mothers voiced differing opinions on having their infants baptized. Some mothers felt that it was appropriate due to the precarious state of the infant, while others felt that it added to their feelings of hopelessness. One mother refused to have her baby baptized because she associated it with giving up on her baby. While the staff were "doing things", the mothers waited anxiously to hear their baby's fate. Time seemed very long, they appreciated someone keeping them informed of what was being done for their baby so that they had some idea of the baby's progress. Lack of information during this time increased the uncertainty for the mothers.

> They [twin] were born around 3:30 and we didn't find out anything till 7:30 that night. I was just in recovery waiting for like three hours and wondering if they were dead or alive basically.

The mothers focused on the critical nature of the baby's illness, dependent entirely on the expertise of health care professionals. The mothers were on "pins and needles" as they awaited the results of the stabilization efforts.

> I was so overwhelmed with her and everything going on. It was just totally unbelievable. Like she was so small. I mean she was so tiny and fragile. She had tubes all attached to herself

Since tertiary level care was not provided at the birth hospital, the infants were transported to another hospital. Despite the additional crisis of being physically separated from their infants, the mothers derived comfort in the knowledge that their babies would be in the unit providing specialized care. Prior to departure, the Neonatal Transport Team visited with the mothers allowing them to touch or hold their infants, gave them pictures, and provided information about the NICU. The Neonatal Transport Team was the bridge between the birth hospital and the NICU. They were called in, stabilized the infants, and visited with the mothers before taking the baby away.

> They talked to me about it. They seemed really good. It wasn't depressing talk, like what they said wasn't gloomy. It was like okay later on she's gonna do this and like they were talking about the future. It made you feel a bit better and that part made you feel okay, maybe she might, the way they talked like there was going to be a future.

Although the mothers had been standing to the side as the resuscitation efforts had been performed, this interaction with the Neonatal Transport Team gave them confidence in those in whom they entrusted their infant's survival. The

physical separation was intensified by the fact of giving over care to health care personnel. The tasks of motherhood; breastfeeding, cuddling and holding the baby were not realized. Even the mothers' abilities to participate in decisions for her infant were impaired by her anxiety.

> There were doctors and nurses--oh the room was just full of people...and then Dr. [ ] he was there and he was telling me things and I said you are going to have to talk to [baby's father]

The physical condition of the mothers following the birth often necessitated their being in hospital for varying lengths of time following the infant's birth. The main objective of the mothers became to visit the babies when their condition and physician allowed it. Leaving the hospital, following birth is exciting for most new mothers, but for the mothers of VLBW infants it increased their feelings of distress.

> I was really upset. Like I was very, very emotional. I can remember that. I cried all the way to the [other hospital]. It was hard for me leaving the hospital without her. Like again you're leaving the [hospital] and everything was coming back from previous pregnancies.

When the mothers finally came to the NICU they were cautious about their initial involvement with their infants. The environment of the NICU heightened their anxiety which further distanced them from participating in their infant's care. The NICU seemed big with bright lights and a variety of noises and activities. The first visit to the NICU remained vivid in the memories of most mothers. The

glimpse of the baby at birth or prior to transport did not prepare them for the sight of infants in the NICU.

> Seeing all the equipment and I don't know it was hard to go in there...and then you went in and seen all these pipes and tubes and everything coming from them and you didn't know what to expect. So then like as soon as we got there the doctor came out and explained... he gave them [twins] a good chance. After talking to him, we felt a lot better and I mean we knew that it was touch and go anyhow regardless of what the doctor said.

The mothers listened to the explanations from the caregivers. They were told about the machines, the beeps, and what was happening with their babies. The physical care had been totally taken over by the professionals. The babies looked so small and fragile, hooked up to all the different machinery; the "jet breathing for her", being on the 'bed that shook", "having saran wrap over her", that it was frightening. The mothers felt that there was very little they could do for their infants at this time. The nurses did attempt to get some involvement by the mothers and advised them that it was okay to touch the babies and they encouraged this as a means of interaction. This was not an easy task. The mothers were afraid that even touching would be traumatic for their small infants.

> I was nervous... I guess seeing her and I was thinking...help us. Just seeing her there knowing I couldn't do anything. I didn't want to touch her in a way because I was frightened to death that I was gonna [hurt] her or something. I was thinking for the doctors and nurses to do whatever they could to help her just to get better.

Monitoring of Formal Care

Although the mothers realized that they had to "give over" the care of their infants there was a sense of them not "giving up" the care. Despite the physical and emotional barriers that interfered with the mother's involvement with their babies, they were carefully watching and monitoring their care. The mothers reflected on the period of time from the transport to the time when they went to the NICU to see their babies. It was difficult for them to be in one hospital and the baby at another.

> The worst was where it was so far away. I wanted to be there. I wanted to go right away but where I was sick...

Initially, the mothers had to monitor the infants care from a distance. They had been told by the Neonatal Transport Team to call at anytime for an update on the baby. When they called, their calls were well received by the NICU staff.

> I had good communication with the Neonatal Unit because they told me anytime I wanted to call, just call. And you know they used to explain to me what was going on with her and everything. what they were doing with her. And they explained to me what the tubes were doing.

The phone remained a vital link with the babies' caretakers throughout the hospitalization. The availability of the 1-800 number made it easier for out of town families to keep in touch with their babies and what was happening with them. This number was used by the mothers and the grandparents as a means of keeping posted on the condition of the baby.

> There was times I sit down and I'd cry because thinking about her and wondering what, you know, how she was doing that day. But everytime I call in, you know, they ease your mind.

The phone was often the source of bad news about the baby also. Usually phone calls in the middle of the night meant that their babies had experienced a critical incident that meant a trip to the hospital or another sleepless night.

The machines that were attached to the infants were a major source of stress for the mothers. The type and number of machines connected to the infants confirmed the seriousness of their infant's condition and the mother's dependence on the expertise of the NICU caregivers.

> They had her on the machine that made her—— they more or less paralyzed her and I guess that had her in her own coma or something, for her to respond to treatment but I was not prepared for it, not one bit. I had to walk away. I will never forget it. Its just not what I expected. I can picture it like it was yesterday.

The "beeping" of the monitors was distressing for the mothers. During the first visits they would constantly watch the monitors and listen for the beeps. The beeps signified that the heart rate had dropped. Over time the mothers learned that the monitors were sensitive and in addition to hearing the alarms or beeps you needed to look at the wave formation and the baby's condition.

The mothers also observed the caretakers to whom they had entrusted their fragile babies. They listened as the doctors and nurses told them about their babies and they saw them effortlessly manipulate the maze of technological equipment in the NICU. But they also saw and heard what was most important to

them; "a caring attitude". The efforts made to make the babies look comfortable in this technological environment was assessed by the mothers.

> I thought it was nice...like I got a nice feeling like how each little corner they tried to make it a little bit personal with teddy bears and signs and blankets and things like that you know... like I had a good feeling....they had her covered up so it was nice and dark inside...kind of a cozy little environment.

The mothers noted the nurse's response to the beeps of the monitors. They were reassured that the babies were being well looked after, and they appreciated the instantaneous responses to the alarms. The nurses not only attended to the alarms but gave the mothers explanations and reassurances as to why the monitors had been alarming.

> And we figured that the nurses knew what they were doing. When the alarms went off they always came over and checked and said there's nothing wrong...its just the medications stopped, they need more or whatever, they were really good...

The mothers appeared to be content with the care given by the staff in the NICU. They were reassured that information was being given to them about their infant's condition regardless of the seriousness of it.

> I felt that the staff are honest, if your baby is doing bad you got to know your baby is doing bad. They don't keep things from you. You should know everything...

<u>Receiving Support</u>

During this time the mothers relied on social support to help them deal with the crisis. At this time all they could do was be with the infant and make sure the

infant received the required care. The mothers talked about the sources of support they used to help them when their infants were critically ill. Supports identified were both formal and informal.

Informal support. The immediate family was identified as the main source of support during this time. The fathers of the babies were there at the time of delivery, while waiting for the news about the transport, and were usually the link between the babies in the NICU and the mothers at the birth hospital. The mothers worried about the impact of this on the father's well-being.

> But it was hard on him [husband] too because you know he had to go by himself and not used to babies and [he] didn't know how I was because I got worse the next day.

Other men waited until their partners were well enough to visit the NICU so they could go down there together. These men supported their partners through this physical separation with the infant that resulted from the NICU transfer. One mother described her experience:

> It was a couple of days before I got to see the babies, to go over to the [other hospital]. He [husband] stayed with me because it was so hard where and we were put in rooms with other woman that had babies [normal] and it was really hard.

The grandparents and other family members were identified as providing both emotional and physical support for the mothers. Having an infant in the NICU necessitated major life style changes in order to accommodate visiting with the infant. Baby sitting of a sibling and preparing meals were two of these

supportive actions provided by family. Parents from out of town sometimes had to rely on family members to provide accommodations for them.

The parent-to-parent support during the initial stages of the NICU experience was limited. One mother recalled a positive experience that she and another mom shared during their time at the birth hospital.

> At the [birth hospital], I shared a room with [NICU mother] we supported each other; talking to each other with someone whose going through the same thing, it was a big help.

On entry to the NICU, overwhelmed by the environmental stimuli, distraught by the sight of their infant, and advised by the nursing staff to stay by their own baby, the mothers did not seek out other mothers.

Formal support. The mothers recognized the nurse's role in facilitating their psychological and emotional adjustment to the NICU. Limited knowledge of the NICU meant that during the initial phases of the experience the mothers did not know how or when to interact with their infants. They were in a strange environment with highly technical equipment and their babies were in critical condition.

> like as soon as we walked in the door she [the nurse] came over and she came along and she spoke to us a nice bit....and we found that throughout the day she was there a lot and she kept coming over and make sure we were okay and everything.

A connectedness with the nursing staff evolved over time but the caring actions were apparent from the initial encounters. Even prior to their first visit to

the NICU mothers had been the recipients of nursing actions that communicated a supportive attitude to them. One mother recalled her first experience with the nurses in NICU when she was still a patient in adult ICU herself:

> Oh my [husband] came in with a grin on his face as big as big could be...the baby's nurse had sent up the blood pressure cuff, her little blood pressure cuff, her name band...like her first little name band and her hat.

The mothers needed information but they also needed time to adjust to the impact of the emotional and environmental factors. The NICU nurses recognized the need of the mothers to share time alone with the fathers and babies and arranged their care to provide for this.

> They got us a chair and whatever and just explained a little bit but they kind of went on and let us deal with it together I guess, for that first little while. And to get use to seeing her [the baby] and whatever..... I thought that was really professional.

The doctors were valued for providing the direction for the medical care for the babies. Mothers acknowledged their presence at critical events; during the transport, upon admission to the NICU, and during times when the baby's condition deteriorated. At these times, the doctors provided information about the baby's condition including prognostic evaluations.

> when we arrived there well the neonatologist was there and you were taken up to the room and filled in on what was going on

For some mothers an early referral to the social worker addressed some of their financial concerns which alleviated some of their worries at this time.

Learning the NICU Rules

The NICU environment was highly structured and the mothers were unfamiliar with the routines. Even routine happenings such as moving the infant's isolette had a traumatic effect on the mother who associated the missing isolette space with her child being dead. In order for the mothers to become involved with their babies they needed to know the care requirements for their infants.

The Neonatal Transport Team provided the mothers with a pamphlet about the NICU that included the phone number that helped the mothers establish a communication link with their babies. When the mothers visited for the first time they were given a booklet. This booklet helped guide them through the events which could occur in NICU. They appreciated that it was written in easily readable terms. They learned about calling in prior to visiting, they learned about washing their hands and putting on a gown before entering the Unit. Perhaps the most predominant rules were those pertaining to visiting.

Although the visitation policy in the NICU is unrestricted for parents and grandparents, the mothers learned that they were expected to leave during rounds, quiet hour, at shift change, and during the admission or deterioration of the condition of another child. All mothers accepted the necessity and importance of rounds, when the NICU team discussed the baby's progress for the past 24 hours and the plan of action for the next 24 hours. A few of the mothers expressed interest in being there during rounds in order to be more informed about their baby's care but most were content with the restriction to the NICU

team. After a few days of coming in early in the morning and having to wait around in the family room or cafeteria for rounds to be over, the mothers rearranged their schedules to accommodate the rounds.

> evenings was the best time to visit, wouldn't have much time between rounds and quiet hour...you could go down there [evenings] and stay then to the morning you had no limit to the time you could spend....

Unrestricted visiting for parents, grandparents, and siblings was endorsed by the NICU staff. However, the mothers often noted inconsistency in the rules. Some staff would bend the rules for substitute visitors while others strictly enforced it. Applying the policy loosely for hospital employees who were relatives of the infant was also noted.

> My sister was down from [City], she wasn't allowed in....I'd always ask permission and always get turned down but yet I'd see other people.. If you're gonna have a rule like that--which I agree to the rule because of different people carrying different germs...I agree with the rule but have it all one way or another...Don't change it for different people

Limiting visiting to parents and grandparents may be traditionally appropriate but often times the mothers relied on the support provided by non family members.

> My friend flew in to be with us, hoping to see the baby. She had had a baby in NICU. My mom stayed out on that day so my friend could go in....my cousin-in-law works at the [hospital] she got in to see her. My friend is upset about that....

Other mothers were supportive of very strict visiting policies. They felt that an unrestricted policy would lead to abuse which could subject the babies to excessive noise or infections.

> We didn't substitute with aunts and stuff. It was just me and my husband. It would be nice but we also knew it could affect their health too if you had all these people coming in and we found that when there was like even my parents or my husband parents come in there was more noise going on too

Another aspect of the baby's routine which mothers had to learn about was the quiet hour. This was an hour in the afternoon when the lights were turned down and procedures were limited to emergency procedures only and visitors were excluded from the Unit. It is a component of developmental care which is meant to facilitate significant improvements in morbidity data. In addition to being good for the babies, the mothers found that the quiet hour gave them a chance to relax. It was stressful being in the Unit all day and the quiet hour was an opportunity for the mothers to go to the cafeteria or the family room for a rest.

> I found it [quiet hour] good. When that happened we just use to go down to the cafeteria and just relax a bit. I mean it was good because we needed a break and we knew that they [the babies] needed a break.

Learning about the Required Care

Initially, the mothers were onlookers of their baby's care. Many were first time mothers having limited knowledge of even normal newborn care. They had missed the opportunity to attend prenatal classes due to the early arrival of the

babies, but with each visit and phone call they learned what the NICU staff considered important.

The physical separation between the mothers and babies had set a distance between mothers and their infants. Although most mothers made an attempt to visit the babies as soon as possible, maternal illness often delayed the visits. The mothers were eager to assume a mothering role:

> and like I was really upset because I kept saying before I saw her.. Mom, she's going to know everybody else, she's not going to know, like, how was she going to know my voice... [on first visit at day 10 of baby's life] I put my hand in, put my finger in her hand, started talking, and she squeezed a little, but I mean ten chances to one that wasn't her knowing me, that was reflex...but I mean to me then it was her knowing me...

The mothers also learned when it was the best time to call to inquire about their baby's progress. They developed specific times when they would call the NICU. Some mothers would call before the night nurse went off in order to get information from the nurse who had looked after the baby for the past twelve hours. Other mothers chose to call after the new nurse for the day was on to see who this was, and to find out the plan of action for that day. The mothers were very interested in hearing the neonatologists' decisions about their child's treatments. They would call after rounds or they would visit after rounds. Often the mothers would call in the night time before they went to bed just to be sure everything was the same.

When the mothers called the unit to inquire about their babies, the mothers learned what the nurses considered important. They would tell them about their infant's weight, the amount of feeds they were getting, their bowel movements, sleeping pattern, and oxygen requirements. Although the mothers felt that in the beginning there was little they could do for their babies they still had a desire to be knowledgeable about their baby's condition. The nurses responded to this need with total disclosure of information about the baby, giving reinforcement and further explanations of information given by the medical staff, answering question to the best of their ability, referring them to the medical staff if necessary, and providing reading material. The nurses became their main source of information about the babies.

> they'd let us know every little thing right down to his weight, if he had his bath...you know if he was starting up on his milk...if they lowered his medication, they'd let us know

The mothers learned what they could do to help their infant even though their physical involvement was limited in this stage. Most mothers were highly motivated to breastfeed their babies. For some the benefits of breastfeeding had been established by their having breastfed a previous child. Some of the first time mothers had also made a decision to breastfeed their child but now that their infant was premature, they wondered if this was possible. Mothers who early in their pregnancies had made a decision not to breastfeed were quite agreeable to try it when the benefits for their VLBW infant were discussed with them.

> I felt really excited, that there was something that I could do.

Once the expressing, pumping, freezing procedure was explained, these mothers gladly supplied the milk. There were challenges; the embarrassment of first efforts that produced tiny, tiny amounts, and seeing some mothers produce bags of milk. The nurses were found to be supportive of the mothers attempts at breastfeeding. When the mothers became frustrated with the small amounts of milk, they were encouraged to keep it up, that this was a common problem, and that every little bit helps.

> Because I mean you feel like you are a failure like you are not doing what you can for your children

Stage 2: Shifting the Balance

The mothers were able to identify a change in involvement in their infant's care as the infant's condition improved and they developed a degree of comfort with the NICU environment. Overtime the mothers became more optimistic about their involvement with their infants. The babies had survived the crises of being born too soon. The mothers had dealt with the shock of seeing their small, fragile infants and had accepted the necessity of the NICU equipment for their infant's survival. They found the caregivers in the NICU supportive and dedicated to the needs of their critically ill patients. Most importantly, the baby's condition had stabilized so the mothers felt that they could gradually participate in the care of their infants without harming them. This stage, shifting the balance, refers to the

process whereby the mothers participated more in their infant's care. The subprocesses associated with this stage include: (a) increasing involvement, (b) maintaining hope, and (c) becoming comfortable.

Increasing Involvement

At first the mothers found it uncomfortable just being in the NICU with their babies and were scared to touch them. Gradually with encouragement from the nursing staff they were assisted in providing care for their infants. They would touch the baby, read to them, or just take comfort in being there and looking at the baby. It was a bit confusing interpreting when it was all right to touch the baby and when it might be harmful to touch the baby.

> we used to be handling her too much. I mean we use to be always constantly rubbing her legs or rubbing her hands. Constantly at that... And they gave us a pamphlet on that and told us how to handle her and what to do with her. Like we could see a difference in her when we started doing it that way...

Gradually the mothers had become keen observers of the baby's condition. They had determined certain criteria to look for when they visited. This helped them establish if their child was making progress.

> Like every day when you go in and look at her and see if she was still breathing and what color...I use to look for color, see what color she was right. Keep looking at their color and her movements, right.

As time in the NICU went on, the mothers became more understanding of the routines and began to participate more in the physical care of their babies. Feeding the baby was an important task to the mothers. Although most of these

babies initially were not fed orally, the mothers participated in feeding by providing the milk and by helping with the tube feedings. The mothers also began to interpret cues from the babies. One of the mothers remarked that the baby's oxygen level stabilized when she talked to her. Another mother expressed an almost spiritual contact with her infant. It was as if she knew the point when she and her baby connected.

> [Baby] her blood pressure was dropped and we couldn't get it back up....so I said she's going to be fine, she's going to be fine. So I went out and I sat down and I talked to her and I talked to her and I talked to her and that night it went up.

One of the milestones in the mothers' participation in her child's care was when she finally got to hold the baby. Having that contact with the baby made their relationship more real. Up to this time, the mothers had minimal involvement. They had gone home from the hospital without a baby--there were flowers and cards but the most important criteria for motherhood--the baby, was missing. They felt empty.

> I think it was a couple of weeks. Oh it was great to know that they were coming along that we could actually touch them. Because when they were there, I mean I knew they were ours but it wasn't the same. There was no contact and like it was a lot better to have them up in our arms...

The moment of holding the baby for the first time was not ideal for all mothers. Some mothers had felt that they had waited too long for the opportunity to hold the baby. Assessment of readiness for holding the baby seemed to be

subjective, at the discretion of the nursing staff. Others felt that the nursing staff were unaware of the emotional impact that holding the baby held for them.

> the nurse who was on that day decided that she felt it was okay for me to hold her and it was going to be the first day that I was going to be able to hold her and I was by myself...but it was just done at the spur of the moment, just like a spontaneous thing.....but thats a really important thing to me..to hold her for the first time...

Kangaroo care, a component of developmental care, has been associated with improving maternal participation in the care taking role. It involves placing the infant in skin to skin contact with the parent. Mothers involvement with kangaroo care in NICU varied, some were encouraged to do it and others seemed to be unaware of the process. Mothers who had participated in the process viewed it positively. The mothers enjoyed the intimacy, having the curtains or screens pulled around the father, mother, and baby, and spending time together as a family. They were aware that the nurse was nearby if needed. The only drawback was the lack of privacy.

> Yes that was really encouraged in the NICU and I found that positive...I really, really enjoyed that and I leaned a lot about the baby, too.

Another area where mothers could increase involvement was in the bathing of their babies. It marked another milestone in the progress of their infants. If the babies were unstable the nurses would do most of the work while the mothers looked on. As the babies became more stable the mothers got into their own routines for bathing their babies. They noted that the NICU nurses

would arrange the bath time to facilitate the mother's participation. However, the first bath was an overwhelming experience for the mothers and they required considerable encouragement and support during the procedure but the feeling of satisfaction following the task was memorable. The ability of the mothers to perform caregiving tasks for their infants was associated with confirming their motherhood status.

> Oh I was a bit nervous where she was so tiny...not knowing if you are being too rough or whatever...I remember that night and being nervous about her breathing as well...I remember being on a high Saturday night after having her out and feeling more like a mom to give her a wash and wash her hair and things like that.....

Breastfeeding. An area where mothers could potentially increase involvement was in breastfeeding. Although most mothers had initiated the expression of breast milk for their babies problems arose when the babies were more stable and were requiring more milk. The most common problem was the inability to maintain a supply of milk. As soon as the babies started "to take off" the mothers could not keep up with the demand. This caused the mothers frustrations and feelings of inadequacies. One mother felt she needed more information about this. She was hesitant to discuss it with the baby's nurse because she felt that the nurses were too busy with critical things. The nurses did support and encourage the mothers to the best of their abilities and often would refer the mothers to the nurse in the Special Care Nursery who was doing

a lactation consultant course. The physical setup to facilitate the mother's expression of breast milk was a source of frustration for some of the mothers. At busy times they often had a long wait to use the pumps or they would have to wait as the pumps were being cleaned. This took time away from their infants.

Maintaining Hope

Although the mothers had cautiously increased their involvement with their infants they were still mindful of the unpredictable nature of their infant's condition in the NICU. With time and experience the mothers came to know the indicators of serious events. They developed coping mechanisms which helped them through these crisis events. The ongoing support from their families and from the NICU staff added to their relatively optimistic view overall.

The mothers used different criteria to gauge when they became more optimistic about the future. For some it was a matter of time, for others it related to the baby's size.

> I think when she got 2 pounds and they started feeding her milk. You know once when she hit 2 pounds like she was a bit stronger..
>
> I'd say it took us pretty close to three weeks. Up to that point when we went in we didn't know what we were going to face that day. After about three weeks, we were getting more hope....

The mothers used the number of machines attached to their infants to compare the seriousness of their infant's condition to another baby. One gauge was to count the number of medication pumps that a baby had on their

intravenous pole. One mother remembered that initially when the babies came in the Unit they had a lot of pumps on their poles but they would have them taken off in a few days, yet her baby continued to have a lot of pumps for a longer time. It confirmed that her baby was still critically ill.

The mothers were watchful of other indicators of the gravity of the NICU environment. Seeing another baby's condition deteriorate or die was very traumatic for the mothers. They became immobilized with fear when they were ushered out of the NICU due to the worsening condition of another child, waiting anxiously in the family room, grieving for the other baby and family while reflecting on the possibility of this happening to their own baby. On entering the Unit, an empty space would verify their worst nightmare; the infant had died.

Ups and downs. Setbacks were common occurrences in the NICU, the infants would be stable for a number of days and then all of a sudden would deteriorate. This was a scary experience for the mothers. Often the setback occurred after the babies had an increased number of apnea spells. Mothers were aware of the occurrence of apneas and bradycardias in premature babies. They knew the nurses recorded each event. It became a routine to check on the number of apneas when they visited or called. If the number of apneas increased, the mothers worried about a setback.

During the setbacks the mothers reported that the nurses were supportive. They reassured the mothers that the setbacks were "normal for premies". "Normal for premies" confirmed for the mothers that the nurses had seen this

happen before and that this was a common occurrence with these small babies. As mothers became more involved in the NICU they associated the apneas and the times when the baby's belly would be swollen and the feeds would have to be stopped, as being "normal for premies".

Downward comparisons. Downward comparison was a term ascribed to the mother's tendency to minimize their infant's situations in comparison to another infant's situation (Affleck, Tennen, Pfeiffer, Fifield, & Rowe, 1987). In addition to accepting the setbacks, these mothers also found solace in comparing their babies to other sicker babies in the NICU. They considered themselves lucky because their babies were doing better and felt sorry for the mothers of the "sicker babies".

> I use to always see them over around her and I felt, God we're really lucky...It was only after I got home that I realized how sick she [our baby] was. But yet I use to go in there and think everybody else was sicker.

Other strategies used by the mothers to remain hopeful for their infant's recovery included being "cautiously optimistic", "turning a deaf ear", and "looking at the bigger picture". Some mother would reflect on the setback and compare it to events that the baby had overcome.

> I just kept looking at the bigger picture. I didn't just let that get me down. Like I kept saying she'll get over that soon.

Mothers found it easier to manage their stress if they were selective in what they heard from the doctor's discussions.

> You know I mean doctors were serious...you know everything is cautiously optimistic but I mean the word optimistic was in there.

Although the mothers found the interactions between parents were rather limited in the NICU, they often took the opportunity to discuss their baby's condition in the family room. Confirming what was happening with their babies as happening to the other babies too established that it indeed was "normal for premies" and helped reassure the mothers.

> The most valuable chats took place when they were kicked out for quiet hour or rounds...we all go up in the family room, set around, talking. and you wonder sometimes, things you know, if you're been imagining things and then talking to other parents and they say no, you know I've noticed that too.

Another supportive measure for the mothers was the attention the nurses gave to make the babies look like "normal" babies. They encouraged the mothers to bring in booties, hats, and receiving blankets for the babies. Laundry bags were kept so the mothers could do the baby's laundry. The nurses took efforts to make the baby look normal in the midst of the technology.

The mothers often referred to the nurses ability to convey hope while giving an honest appraisal of the critically ill infant. It was frustrating for the mothers to have the babies stable and then have a setback where the baby's life was again in jeopardy. The nurses had an ability to convey support for the mother without undermining the seriousness of the situation.

> I thought we were going to loose her that time she was really sick. But at the same time you know some of the nurses...the minute they came in... "she's a little

> better today, you know she's still not you know 100%" You know they were honest but they did come over....

The mothers remembered that during setbacks even the nurses who were not assigned to the infant came by to see how the baby was doing. The mothers realized that the nurses often called in even when they were off duty to inquire about a sick baby. This supportive action helped the mothers maintain hope.

Medical support. The mothers acknowledged the supportive presence of the neonatologists during periods of crisis. The mothers were given the information about what was happening to their infants but the treatment options were conceded to the physicians.

> We let them know that to do anything to him they don't need our permission as long as it could help him. I mean they're doctors. They know what they're doing...they don't need any permission.

The mothers varied in their opinions on the availability of physicians. While most mothers found that the doctors were available to them, some did express dissatisfaction with access to medical opinion. The availability of the doctors during times of crisis was appreciated but the mothers also expressed the need to be reassured by the neonatologists even when the babies were stable.

> Sometimes its kind of nice to hear from the doctor.... like I know the nurses know their stuff and sometimes the doctors would ask the nurses what do you think because they use to spend so much time with the babies but sometimes it just...I don't know you just like to hear it from the doctor. I guess its just, you know, the way you're brought up"

> I tried to speak to her doctors and then she had so many doctors, one week it was --- then another week

> it was --- and then it was another doctor and another doctor so I just couldn't understand how she kept getting septic...

The mothers felt well informed about any surgical procedure being done on their infant. They appreciated that the doctors used drawings to explain the procedures that would be done on their infants. During this time of increased maternal anxiety the visual methods of communication aided in their understanding.

> Oh yes, a doctor would take us in a separate room and he'd go over everything and make sure we knew---he'd explain, he'd show us in a diagram or they'd draw it out...the doctors would really go over it and make sure we understood. They'd ask us a few times if we understood everything they were doing and how they made the incisions.

Occasionally mothers felt that they had not been informed about a procedure being done on their children.

> Sometimes ---like I'd go down and I'd ask a few questions and there be things done that I didn't know were done and like he had to be given a blood transfusion and that was upsetting...but when I went down like they had it all hooked up and stuff like that and I got all upset.

Becoming Comfortable

This substage defines the process of reciprocal trust which developed between the mothers and the NICU nursing staff. The mothers spoke of the nurse's role in influencing their ability to assume a mothering role. During the process of Becoming a Mother in the NICU, the most significant relationships

developed with the nurses, the staff who spent the most time with the infants and mothers. Over the course of this relationship the mothers had monitored the performance of the technical care and also the caring approach used by the NICU nurses. They were pleased that the highly technical care requirements for their infants had not distanced the nurses from caring for the mothers and their families. This caring approach displayed by the nurses was seen as a major force in reducing the anxiety of the mothers in the NICU. The mothers noted the informal and relaxed approach of the nurses that enhanced the development of this trusting relationship.

> Oh excellent, excellent. I haven't a bad thing to say about them. Because they were hands on very people friendly. Like I could go in there and sit down and it was like sitting down with one of my best friends.

It was evident from the mothers' stories that the nurses became the constant in the NICU environment. The mothers seldom spoke of the other health care providers referring consistently to the nurses as the ones who provided the care that the mothers valued. The nurse's caring was extended beyond the mother to the father, siblings and other family members.

> Oh yeah, still different nurses but no they basically did the same in there. They all had that openness, that friendliness. And like I said they were great with [my other child]. It was like they always gave that extra effort to make you feel a little bit better.

The mothers recognized the ability of the nurses to tune into their needs during times of crisis. The companionship and presence of the nurses reinforced

the mothers ability to maintain a presence in the NICU and offered some relief from the uncertainties and anxieties inherent in Becoming a Mother in the NICU setting.

> They always make you feel comfortable and they sit and say well how are you feeling today or they just sit down and they talk to you. And it wasn't just about the babies like they made conversation about anything when they [the babies] were really sick. That was good because there was a lot of times I didn't want to hear you know well the baby is having a bad day you know or he's really sick today and I just wanted to know that and that was it. And we got to a different topic.

The nurses were in tune not only with the emotional needs of the mothers but with their physical needs as well. Some of these mothers were balancing caring for a child at home with trying to take on the mothering of an infant in the NICU. It was tiring. The nurses acknowledgment of the mothers' physical discomforts conveyed to the mothers feelings of support and caring.

> They knew I wasn't going home. They use to say go out there and lie down because they've got a little cot out there....they use to keep asking me "are you drinking your eight glasses of water today" because they knew I was having a problem trying to keep up with it [breastfeeding].

Humor was used very effectively by the NICU nurses to help promote and maintain the mothers well being while in the NICU.

> I got up 3 o'clock in the morning and called down...now you're liable to hear....what are you doing calling down here this hour of the night, do you know we're all in our isolettes having a nap.

Since the mothers' interactions with their infants were limited by the equipment, the efforts of the nurses to make the babies comfortable was appreciated by the mothers.

> ..you go in somedays and they have on little hats, little boots...and she always looked so comfortable you know I think the effort was made to really make her comfortable.

The nurse's attentiveness to the technical aspects of the infant's care was valued by the mothers. They acknowledged the nurse's continued vigilance of the beeps and their checking of the equipment. Overtime, the mothers were able to tell the level of expertise of the nurses in manipulation of the equipment in the NICU. They noticed that the nursing care was always overseen by senior staff. They had confidence in the skill of the nursing staff.

> Oh yeah, I felt very trusting. Because even if they were younger, more inexperienced nurses there, there were always others around. Like I always felt that if there was something that they didn't know they could ask and I did witness that.... And it seemed they gave the more serious cases to the more experienced nurses. Babies on ventilators and things like that would get you know....it seemed like the more experienced nurses were with the more serious case babies...

They noticed that the nurses were carefully recording all the happenings with the baby. Most importantly, the nurses were always there by the babies.

> Oh yes, we found it more comfortable, knowing that they were going to be looked after and they were going to be all right.

The mothers recognized and appreciated the encouragement and the guidance received from the nurses as they had learned how to care for their preterm babies.

> I don't know if we looked like we knew what we were doing but they knew that we were comfortable enough that we could take the baby out of the isolette and we'd bath her and they would change the isolette.

With the babies in the NICU for weeks and sometimes months many important events in the lives of the mothers and their families were spent in the hospital. The efforts that the nurses made to recognize those special days and "make a big deal" for them were meaningful for the mothers. Father's Day, Mother's Day, and birthdays were celebrated with special mementos and cards, personalized with pictures, from the babies. It also pleased the mothers to hear that the nurses liked to take care of their babies.

> You know some of them use to say "Oh got my girl tonight"
> There was one nurse in there she was a real sweetheart...oh my, she kept me going, I think. Yeah, she was some good...she was with her all the time but every time that she'd come on [my baby] was the one she hoped she'd get..

Special relationships developed between the mothers and some of the nurses; one mother referred to one nurse as "the best of the best", but most importantly she recalled the relationship that was consistent with all the staff:

> The nurses, I'm telling you they're sent from heaven"
>
> There was never any doubt like it was always in the back of my mind that they [twin] were really sick and

> something serious could happen. But they always made you feel comfortable. And they explained everything to ya and it was like they put the doubt away.

The reciprocity of the relationship was echoed by most mothers as they described the feelings that had occurred between themselves and the nurses in the NICU. A mutual feeling of respect had developed between the nurses and the mothers.

> They treated us like gold..they treated us like part of our family. And they are...and they are looking after your child.

Stage 3: Making Progress

The third transition in maternal involvement with their VLBW infants came when their infants were stable enough to move from the NICU. As the infants showed signs of progress; weight gain, the removal of the ventilator, tolerating feedings, decreases in the occurrence of apnea and bradycardias, it signaled a time to move on to the convalescing unit, the Special Care Nursery (SCN). The transfer to the SCN induced ambivalent feelings for the mothers. They were happy that their infants were improving but they felt uncomfortable leaving the NICU staff and the care that had been given to them and their babies. The mothers recalled feelings of uncertainty about this change in environment. They felt anxious about having new caregivers for their infants. This stage, making progress, has three substages: (a) moving on, (b) being disorientated, and (c) anticipating going home.

Moving On

The mothers appeared to have mixed feelings about being transferred to the Special Care Nursery (SCN). They had developed a special relationship with the staff in NICU and felt trusting of the care provided. They had established routines for visiting and for participating in care and they were comfortable. These feelings of concern were mixed with feelings of relief. Moving on to the SCN meant that the baby was getting better and was heading home. The NICU nurses maintained contact with the babies and their mothers after they left the Unit. They would often go to the Special Care Nursery (SCN) to check on the baby's progress. The mothers valued these visits since these nurses had known the babies intimately from birth and could accurately access their level of improvement.

All mothers considered the graduation to the SCN a milestone in the NICU experience. The mothers felt trustful that the NICU staff would only transfer the babies when they were ready. Certain criteria had been met: their weights were up, the oxygen tubes were out, they were breathing on their own and "they were on the road to recovery".

> the best day was when they left the Unit. I mean you knew that when they went to the nursery that they had their proper weight up, they were coming along. The nursery was more or less teaching you how to look after them.

Being aware of the transfer and participating in it was important to the mothers. yet it was sometimes treated as commonplace by some staff.

> It happened before we even knew it. before we were down there..it kind of would've been nice even for us to have been there to move, see her being moved to the Special Care Nursery. Of course, we went down, but it would've been nice to have [been there]...we weren't really doing anything else.

Ambivalence about leaving the NICU was a common finding. The mothers expressed difficulty with leaving the familiar and going to the unfamiliar. They expressed anxiety created by the absence of the NICU nurses.

> Oh yes, I felt good she was going out there but still you are really apprehensive because you are so use-- we were ten weeks in ICU...these people were our families you know and then you are going out to people who you don't know who they are...you know nothing about them.

Being Disorientated

The first major difference the mothers noted on entering the SCN was the physical space. It was so small and if they had a lot of babies there, it seemed cramped and crowded. The mothers spoke of advantages and disadvantages to the size of the Unit. One of the advantages of being in a confined space was the close proximity to other parents. In the NICU parental contact was limited to "chats" in the family room. In the SCN, the mothers got to know their neighbors and developed friendships. They became supportive of each other and would accompany each other to lunch or talk in the family room.

> But its like you got such a close bond. You got this big, big thing in common. That you didn't have, you never had even with friends you had forever.

The support of more experienced parents helped mothers deal more realistically with their expectation for their babies. The more experienced mothers reported giving advise to the new mothers.

One of the limitations of being in a confined space is the realization that the conversations and activities of all are under scrutiny. Mothers felt uncomfortable when the nurses would congregate around the desk or were chatting about shifts or annual leave or being floated to NICU. The mothers wondered if the stress related to these issues would affect the care of their babies.

Many of the mothers had developed routines for caring for their babies in the NICU and were not aware that the rules had changed when they transferred to the SCN. Providing physical care for the baby had been supported by the nurses in the NICU. The mothers felt comfortable in going in the NICU and doing certain tasks under the supervision of the NICU nurses. In the SCN, the mothers did not feel encouraged to continue these practices. The mothers felt frustrated by the changes and their lack of information about the changes. Often the mothers did not accompany the infants to the SCN and were not given an orientation to the unit.

> like the first night, she got moved in the afternoon, so that evening I got down I was in a routine out in the NICU...but when I got there, its like no we don't do it that way...its like the whole routine was totally switched on me

Many mothers had developed ritualistic practices in relation to their phone calls; in the morning, after the doctor's rounds, and before bedtime. One of the most important calls was following rounds to hear "what the doctor had said". They had previously had the "whole run down" and plan of care for the next 24 hours from the NICU nurses. In the SCN, they experienced frustration not only with the limited information but with a sense that their frequent calls were not appreciated.

> Now first when we went out there they were saying now you call anytime...but we felt that if I called every hour or every couple of hours, I heard them talking about another parent [They said] "now thats the third time she called, the past so many hours and her baby's the same, I don't know why she's calling" and I know they were probably saying the same thing about us calling

Compounding the frustration with the changes in routines was the discontinuity of practices which had supported the bonding of mothers and babies. Mothers who had participated in kangaroo care in the NICU felt that the nursing staff in the SCN discouraged them from continuing this practice. Mothers who had become confident in some of their caregiving roles became discouraged.

> Honest to God, that night I had the baby up and it was just getting to the stage that I was allowed to take her up and in the NICU was encouraged to do kangaroo care and I just had her up in the Special Care Nursery and the nurse came by and said, "you are overstimulating your child put her back" And I was just oh my...I was really hurt, so it was just different I guess.

Some of the mothers felt that NICU nurses had encouraged their independence and recognized their ability to manipulate the monitors. They found that this had changed here, too.

> You were told...don't touch the monitor, don't touch the baby.

One of the most drastic changes for the mothers was the variation in the nurse-staffing patterns. In the NICU, the mothers had become secure in the presence of one nurse providing continuous care for her infant. In the SCN, there was one nurse for three or four babies. One mother even recalled there being one time when one nurse had six babies in the middle room. The mothers indicated that because the nurses had other responsibilities; other babies to care for and other tasks to perform, they felt they could not rely on them to care for their babies. The mothers associated the low levels of staffing with a decrease in the quality of care.

> I use to be home at night wondering if she was being looked after. I use to say what's she doing...is her machine going off because she was always having apneas and that was scaring me too. Because I was saying if she has one and they don't go in right away, what happens, she's dead.

Additionally, staff shortages meant that the mothers were expected to take on certain tasks without the appropriate direction. The mothers felt that the staff did not orientate them to the routines and expectations of the SCN.

> I think I would have dealt with it better if I had been orientated to the Special Care Nursery--I wasn't. I was just...your baby is in there. And in there its pretty self serve. Get what you want, get what you

> need...like I'm not that out going of a person to just go root around and go into places that maybe I shouldn't be...

Another frustration for the mothers was the sense of loss of the value previously ascribed to the family support system. In the NICU, the mothers had become accustomed to the presence of certain family members and the inclusion of these family members in the baby's care. Two of the mothers reported that their substitute family members who had visited regularly in the NICU, were prohibited from visiting in the SCN. Lack of recognition of the role of the immediate family was observed.

> They stopped my brother and sister from going in and we were told "when the baby was really sick out in the unit [NICU], then you needed them to go in" but I said "this is not only for [baby] this is for them too, they need to see [baby]

The mothers had anticipated that as the babies got bigger and less susceptible to infection they would be able to have more visitors. Even the possibility of having the babies viewed at the SCN door was appreciated by the mothers. Mixed messages given to the mothers about their visiting rules led to more discontent with the SCN.

> I tried to get everybody to come the same time because sometimes you get the feeling that the nurses, didn't , you know, want you to take her to the door or whatever...Maybe I'm just paranoid, I don't know.

The reduction in staff patterns resulted in strict adherence to certain routines in the SCN which limited the mother's involvement with their babies. The mothers

had been used to having flexibility in their schedules in the NICU, which allowed them to have access to their infants at their discretion. In the SCN certain tasks were done at set times, and if the mothers were not there at those times she missed the opportunity to participate. The mothers were resentful of the change accompanying their move from the NICU to the SCN and they could not understand the changes in the rules. It seemed that there was no explanation for the changes that had occurred.

> But here you are, your baby was in the Unit one day and out in the nursery the next day so why don't they get the same care out in the nursery, which they don't..

Some of the mothers were more positive about the move the SCN. It was seen as being less stressful and a "happier place" where the main focus was on discharge planning. They were content to learn the care for their infants under the supervision of the nursery staff.

> The nursery was more or less teaching you how to look after them. Thats what we found the nursery for. Like they showed us how to feed them and how to change their diapers and give them their baths and like that. We found it was a learning experience out in the nursery.

Anticipating Going Home

As the mothers adjusted to the SCN they became more focused on getting the babies ready for home. The mothers noted the improvements in the baby with the gradual disappearance of the support equipment; the intravenous lines were gone, the nasogastric tubes came out, and the babies were feeding by

mouth. Another milestone was the transfer of the baby from the isolette to the crib.

> But the most exciting day I had was the day I went in and she was out in a cot. She was out of her isolette and she was in this cot and...like they had pajamas on her and she looked like a real baby, then.. I didn't sleep that night.

With the babies in the cribs and attached to fewer tubes, the mothers were comfortable in handling them. They were spending more time there and were doing the baths and feedings. There was a sense of increased activity in the nursery. The mothers were doing "more hands on" care. The mothers were taking on the tasks of motherhood with enthusiasm. They did not express any anxiety about their impending discharge from the hospital. Indeed, as the mother's confidence in doing the care for their babies increased, the desire to be home with their babies became pivotal.

> Being at a point where you know when they are ready to go home

CHAPTER 5

DISCUSSION

Maternal involvement with a very low birth weight (VLBW) infant is a complex process. The process is influenced by a number of conditions. Some of these have already been identified in previous research while others have not been examined in any depth. This chapter presents a discussion of some of the key conditions that may promote or hinder maternal involvement and what may account for some of the differences. A strength of grounded theory is that it does permit the researcher to look at differences in social interaction in various situations.

Stressors in the NICU

As with previous research results from this study indicate that many other aspects of the NICU are stressful to mothers and do affect their involvement with their VLBW infants (Catlett, Miles, & Holditch-Davis, 1994; Miles, 1989; Miles, Funk, & Kasper, 1991; Miles, Funk, Kasper, 1992). These include: (a) the appearance of the fragile, sick baby, (b) alteration in the parental roles, and (c) to a lesser extent, the sights and sounds of the physical environment in the NICU. The study of Wereszczack, Miles, and Holditch-Davis (1997) uncovered stressors relating to the communications patterns between the NICU staff and mothers. Conditions which the mothers in the present study identified as having contributed to their involvement or non involvement with their infants include: the infant's condition, NICU environment, rules and routines, visiting, breastfeeding,

coping mechanisms, social support, decision making, and distress over the transfer from the NICU to the intermediate level nursery.

Infant's Condition

The mothers' perceptions of their infants' conditions was a critical factor in maternal involvement, but equally important was how the mothers monitored their infants' condition to help with their involvement. In the early stage, just after birth when the infant's health status was critical and precarious, the mothers were willing and relieved to have highly trained professional caregivers take over the infant's care. What the mothers realized at this time was if their infants were to have any reasonable chance of survival it lay with the technological expertise found in the NICU. Involvement at this time was as a very interested bystander as they watched what occurred.

The perceived physical condition of the infant became an important marker by which the mothers could gauge their level of physical involvement with their infants. As they saw their infant's condition improving it signaled to them that greater involvement was possible. What does not seem to be identified previously are the signs that mothers use to help them with this decision. Lay conceptions of health are different from health professionals, therefore in the NICU mothers had to combine their lay knowledge, observation of their infants, and information from nurses and doctors to increase their involvement. Information on the infant's condition was continually sought from NICU staff. The use of such objective criteria as number of machines their baby required and

number of medication pumps is a good example of how they used observation as a way of assessing their infant's condition. As health professionals we may not be aware of the extent of patients' observations and how they use these observations in self-care activities.

Mothers who are less able to use these observations as a measure of increasing involvement may be the ones who seem less interested in their infants and becoming involved in their care. Alternatively they may be the mothers who are less attuned to the physical condition of their infants and when it is appropriate to pick up or hold their infant. They may be the mothers who experience more anxiety about their infant's condition because they cannot monitor them as well.

NICU Environment

The influence of environments on human health is well documented (Malkin, 1992; Watson, 1999). Usually the focus of research on the NICU environment has been on the effects on the infant (Als et al., 1986; 1994; Gottfried et al., 1981; Gottfried, Hodgman, & Brown, 1984; Jones, 1982; Merestein, 1994). However, this research has demonstrated how important environmental factors are for mothers and their involvement with their infants. The mothers described how the environment not only influenced their involvement with their infants but with other parents and caregivers.

Environmental conditions also served as cues to their infant's possible condition. Even in the NICU patients develop a sense of personal space and

there is a feeling of displacement or loss when they are moved from this space. When mothers entered the NICU and their infant was not in their usual place they felt a sense of panic; that something had happened to their infant. All the mothers described the way the view of the NICU changed from their first visit, when it seemed so big and impersonal, to subsequent visits as they became used to their infant's place and felt at home.

Spatial comparisons were made between the NICU and SCN and how interactions with their infants were constrained by the space available. Parent's privacy was more easily attained in the larger space of the NICU. In the SCN where mothers and nurses were forced to be closer together because of space limitations mothers overheard more of the nurses' conversations. This seemed to heighten anxiety on the part of some of the mothers. In the NICU where space allowed greater distance between mothers and nursing staff the same phenomenon did not appear to happen.

Rules and Routines

Rules and routines of an institution govern much of the interaction that occurs and certainly affects maternal involvement with infants in the NICU. Generally, the mothers were able to accept and even respect the rules and routines once they understood what they were and the logic for instituting them. They could even see that these rules and routines worked to their advantage. For example, quiet hour was a time for uninterrupted rest for the infant and it served somewhat the same function for many of the mothers. It gave them a

chance to take a break from whatever level of care they were able to assume for their infants at a particular time. This might have been very important when the infant was critically ill and involvement was limited to sitting by their infant and watching over them.

Quiet hour also served another unanticipated role. In the NICU mothers were discouraged from interacting with each other and expected to remain at their own infant's bedside. However, when they had to leave the NICU for quiet hour they found themselves in each other's company either in the cafeteria or in the family room. It was in these places they were able to meet, talk, and compare their experiences. It gave them that social support that comes from talking to someone in a similar situation.

One of the rules examined in previous studies is the visiting policy. All the mothers commented on rules related to visiting. Variations in the rules included lack of flexibility, inconsistencies between nurses in the interpretations of the policy, and giving special considerations to some family members or to hospital employees if the infant was related. These findings are similar to those reported by others (Griffin, 1998; McHaffie, 1991; Prudhoe & Peters, 1995).

Breastfeeding

All mothers in the present study attempted to provide breastmilk for their preterm babies. Unfortunately, the duration of their breastfeeding was similar to the breastfeeding attempts by other mothers of VLBW infants (Hamelin, Saydak, & Bramadat, 1997; Hill, Brown, & Harker, 1995; Jaeger, Lawson, & Filteau,

1997). Mothers were frustrated by their inability to maintain a milk supply for their babies. When the babies were on full feeds the mother's supply became inadequate. Only four mothers were breastfeeding at discharge. One of these mothers had hired a lactation consultant while another two mothers had successfully breastfed an older child. Hamelin, Saydak, and Bramadat's study (1997) also found that only 50% of preterm mothers were successful in establishing breastfeeding before discharge.

The mothers in the present study appeared to have the support of the nurses in the NICU to initiate and maintain their breastfeeding enthusiasm. However, the guidelines for successful breastmilk expression may not have been consistent. Many of the mothers reported different schedules for expressing their milk with some mothers only expressing three to four times a day. Research by Auerbach and Walker (1994) has recommended an optimal pumping frequency of at least eight sessions in 24 hours for approximately 15 to 20 minutes maximum time per sessions.

Coping Mechanisms

Similar to findings by Affleck, Tennen, Pfeiffer, Fifield, and Rowe (1987) some of the mothers in this study found "solace" in making a downward comparison to other sicker infants in the NICU. These mothers considered themselves lucky and felt sorry for the mothers of the "sicker" babies. Lasby, Newton, Sherrow, Stainton, and McNeil (1994) reported that making downward comparison gave the mother a feeling of guilt over her selfishness in thinking "at

least it's not me". These feelings of guilt were not substantiated in the present study. An opposite comparison was also found in this study whereby the mothers would compare her child to another child in the NICU and realize that her child was more critical and would probably be in the NICU for a longer period of time.

In addition to "downward comparisons", the present study identified other methods for maintaining hope, not previously identified in the literature. These include the mother's looking at the "broader picture", "turning a deaf ear", and "being cautiously optimistic". During setbacks, the mothers would remain optimistic for their infants by focusing on the fact that the baby had survived worse ordeals and would do so again. Also, the mother would often become selective in listening to information being told about the seriousness of her child's condition.

In stage two of the current study; shifting the balance, the mothers identified *their pleasure in being able to be involved with their infant's physical* care. It included the mother's contribution to the care of the baby; learning about the baby, ensuring that the baby was receiving the best care, doing things for the baby, and maintaining hope. Hughes, McCollum, Sheftel, and Sanchez (1994) defined this process of "focusing on the infant" as a coping strategy to deal with the stressors of NICU. They differentiated between active forms of coping; monitoring the infants' condition, comforting the infant and visiting the infant and passive forms of coping; deriving comfort from being with the infant and developing an attachment to the child.

Social Support

In the present study, mothers identified the support provided by spouses, grandparents, caregivers, and other parents. These mothers perceived a lack of staff support for parental interaction in the NICU. However, mothers did recognize that over the course of the baby's hospitalization special friendships developed with other parents. Informal "chats" in the family room were recognized as comforting and informative. Mothers would often confirm their infant's progress or activity with another mother who had lived the same experience. This use of an experienced or veteran NICU parent, in a one-on-one interaction has been advocated as being helpful for parents (Jarrett, 1996a; 1996b; Lindsay et al., 1993; Roman et al., 1995). Parent support groups were not available to mothers in this study. However, other parents have had varying degrees of success with these groups; claiming that they take too much time away from their infants (Stauber & Mahan, 1987).

Decision Making

In the present study, the mothers wanted all the information in relation to procedures, they sought participation in the decisions, but they felt decisions in relation to treatments were best made by the doctors. The mothers did not identify any dissatisfaction with their involvement with medical decision making. Similar findings were reported by Affleck, Tennen, and Rowe (1991). The main reason for wanting information in the current study seemed to be related to monitoring the infant's condition rather than as a basis for decision making. Even

though some of the infants of the mothers interviewed had varying degrees of disabilities, they did not question any of the decisions doctors made in the NICU as did the parents in Pinch and Spielman's studies (1993; 1996).

If the attitudes of the nurses were the same as that found by Lee Penner and Cox (1991a) which was conducted in the same hospital and eight years ago, the mothers did not detect any pessimism from the nurses concerning the outcomes for their infants. However, it is acknowledged that attitudes could change in that period as outcomes may have improved. Contrary to findings in the present study, there is an emerging body of research suggesting that parents are experiencing frustration at their lack of involvement in decision making in the NICU (Pinch & Spielman, 1993; 1996; Scholmann & Fister, 1995).

Transferring from the NICU

The participants in this study reported intense anxiety relating to their transition from the NICU to the SCN. They expressed ambivalent feelings about leaving the NICU; happy that their babies were well enough to be transferred but reluctant to leave the familiar setting of the NICU. Many of the mothers remained critical of the care in the SCN throughout the remainder of their infant's hospitalization. Hayes, Stainton, and McNeil (1993) also defined maternal feelings of uncertainty relating to the anticipation of their infant's discharge from the NICU. These mothers felt that the uncertainty which they had felt when their infants first entered the NICU had resurfaced.

The results of the study of in-hospital transfer by Kolotylo, Parker, and Chapman (1991) reported similar findings to the present study. Three themes were identified by these parents following their infant's transfer to a special care unit. These were (a) feelings of relief, accompanied by concern, fear of the unknown, and feelings of alienation; (b) dependence on familiar things, and people; and (c) feelings of helplessness.

Findings from studies relating to retrotransfers or back transfers from an NICU to a community hospital report problems for the parents which concur with the present study (Flanagan, Slattery, Chase, Meade, & Cronenwett, 1996; Kuhnly & Freston, 1993; McDonald-Gibbins & Chapman, 1996;). McDonald-Gibbins and Chapman's study found that parents felt "left in the dark" while waiting for the transfer and about the transfer itself. The mothers in the present study reported a similar lack of participation in the actual transfer of the infant to the SCN. Kuhnly and Freston (1993) describe a back-transfer within a crisis model. It had three phases (a) precrisis, (b) transition, and (c) acceptance. During the transition phase several similarities with the present study were discovered. These included factors which lead to the crisis: changes in care giving practices, environmental changes, and parental feelings of powerlessness or disempowerment.

In conclusion, although there are many similarities and differences found between this study and other research studies, the most salient aspect of this study which differentiates it from others is a better understanding of some of the

conditions that promote or inhibit maternal involvement with their VLBW infants in an NICU environment and what that process is like for mothers.

CHAPTER 6

IMPLICATIONS FOR NURSING

Evidence-based practice in nursing is dependent upon research that will assist us in understanding and improving the care we give to our patients. This chapter presents a discussion of the implications of the research for improving the care we give to mothers of very low birth weight (VLBW) infants in a neonatal intensive care unit (NICU) and to the infants and other family members. Suggestions are made for improving nursing practice, policy, administration, education, and research.

Implications for Nursing Practice

Nurses in practice are the main target audience for the research findings. The study has identified a number of practices that could be continued or improved to enhance the quality of care to VLBW infants and their mothers. One of the highlights of this research was the identification of events which signaled to the mothers significant improvements in their infants. The milestones in the infant's NICU experience that mothers recognized as significant were: holding the baby for the first time, participating in bathing the baby, graduating to the nursery, and graduating to a crib. There is a need to be more cognizant of the important psychological impact these milestones have for the mothers. For example, although holding the baby for the first time was a major milestone for the mothers, sometimes it was an overwhelming experience if the mother felt the baby was

physiologically unstable. Therefore the policy of encouraging mothers to hold the baby should be balanced with the parental desire to participate.

The mothers remembered being asked to leave the NICU during rounds, quiet hour, and during report. The mothers realized the necessity and importance of these rules. However, an effort should be made to keep to certain time frames, in order to decrease the amount of time that the mothers are away from their babies. The time devoted to the daily plan of care for the infants during "rounds" was highly valued by the mothers. An effort should be made so that the time does not fluctuate from week to week, and from physician to physician because this limits the time available for parents and makes planning of visiting difficult for them. Another consideration would be the inclusion of parents at the rounds. This would provide parents with access to information and allow them the opportunity to have more input into their infant's care. Decision making has been noted to have a 'top down' approach. The mothers acknowledged that they were informed about the treatment decisions but allowed the physician to make decisions. Involvement of parents in decisions regarding all aspects of neonatal care from the beginning of their infant's hospitalization has been recognized as preparing them for ethical decision making and for decision making post discharge (Stark & Thape, 1993).

Coping with a critically ill infant was found to be extremely stressful for the mothers. When the mothers were asked to leave the NICU when another baby deteriorated it added to their distress. They feared for the other child but also

grieved for the possibility that it could happen to their child. If there was an empty space when they come back, it confirmed their worst nightmare, another child had died. Acknowledgment of maternal concerns regarding the setbacks of other infants in the NICU needs attention.

This study found differing opinions among the mothers on their involvement with other parents in the NICU. While some mothers wondered if other parents wanted them looking at their baby during the critical phase, others felt that the nursing staff discouraged parental interactions. It is suggested that the individual opinions of parents might add insight regarding their need for support of other parents at this time. Additionally, some of the mothers in this study found that the financial support available through the social worker had not been realized during the early stages of their infant's hospitalization. Overtime, some mothers felt themselves to be a burden to the family and friends who were providing accommodations for them in the City. All parents need to be referred to the social worker early in the NICU experience.

Another area for improvement is the low levels of successful breastfeeding at discharge, despite having a highly motivated group. Other hospitals have instituted the services of a lactation consultant to help resolve similar problems. It is recommended that a lactation consultant be included as part of the NICU team who would be responsible for initiating a breastfeeding program for the neonatal area.

This breastfeeding program should include:

- current recommended practices for the expression of breastmilk: (a) type of pump, (b) pumping technique, (c) frequency of pumping, (d) availability of pumps, and (e) maintenance of pumps
- an education program for nurses
- daily support and guidance for mothers
- policy development

One of the most stressful periods for the mother was the transition from the NICU to the SCN. Nurses from both areas must identify key differences in practices and work toward consistencies when possible. The most outstanding differences reported by the mothers in this study include: visiting privileges, bathing routines, holding baby practices, manipulating the monitors, and phoning regimes. Greater preparation of the mother for the transfer to the SCN is required. This planning could begin, when realistically possible, in the NICU. The mothers should be given tours of the nursery, introduced to the staff, and given information about the practices and routines. The mothers must be reassured that the baby is no longer critical and does not require intensive care technology and one-on-one care. The mothers could be encouraged to express their feelings about the transfer and efforts must be made to gain an understanding of their needs. Efforts must be made to ensure that the SCN nursing staff know the parents and understand their level of involvement in the baby's care.

A neonatal nurse, who was also the mother of a preterm baby, recommended the use of primary nursing to help decrease miscommunication in the NICU (Mooney-Smith, 1987). The findings in this study would suggest that this might be a helpful strategy to bridge the communication gap and ensure a seamless transition from NICU to the SCN. The primary nurse could coordinate the move from the NICU to the SCN.

Implications for Nursing Policy

There was one major area identified for policy development. It was concerned with inconsistencies in the visiting policy. The visiting policy needs to be carefully examined and revised to assist mother's involvement. Mothers ought to be allowed to define their family support members. Some circumstances will arise that necessitate flexibility in rules. Policy that is fair to all could accommodate most mothers' needs.

Implications for Nursing Administration

It is suggested that administrators of neonatal units evaluate discrepancies between NICUs and SCNs identified by the mothers, such as staffing patterns. One of the main concerns was a change from one-to-one care one day to one nurse caring for three to four infants the next day. Since this appeared to be a major concern and source of anxiety for all mothers interviewed, it is reasonable that this and other practices that were anxiety producing be examined.

A second area for administrators to examine is consistency in what maternal involvement is permitted and encourage in the NICU and SCN. Mothers

found it difficult after they were used to one set of rules that encouraged their active participation to have to change to more restricted participation when their infants were transferred to the SCN.

One contribution of this study is to program development. A component of program development is evaluation and this study provides qualitative data on the care being provided in the NICU. It has identified areas the mothers felt are beneficial to the care of VLBW infants and their families and areas which could be targeted for improvement. Swanson and Chapman (1994) suggest more qualitative evaluation research be done to understand what happens within programs and to capture the multiple realities that may be hidden in a quantitative evaluation.

Implications for Nursing Education

Critical to the education of a nurse who is considering a career in neonatal nursing is an awareness of the physical and emotional needs of mothers of VLBW infants. This study has highlighted some of those needs that mothers reported throughout the various stages of the process of involvement with their infants. The mothers recognized and reported nursing actions that were significant to their adjustment to the NICU environment. These included the nurses' constant presence, consistent approach, provision of opportunities for involving mothers in the infant's care, and their ability to provide support during setbacks in the infant's condition. The support they really appreciated was their focusing on the future while being honest, and providing information on the

infants. Awareness of these values could be incorporated into orientation programs for nurses in NICUs. Nurse educators need to emphasize at the entry point for neonatal nurses that nursing care extends beyond the provision of technical care; although the technical care is important and is carefully monitored.

The study's findings are not limited to staff education as knowledge gained from the research has implications for nursing educators in undergraduate and graduate programs. Empirical knowledge has been recognized as providing essential information for the care of children and families (Pridham, Broome, Woodring, & Baroni, 1996). The study has identified nursing interactions which mothers found essential for their involvement with their infants and conditions under which this involvement is fostered. Although specific to the NICU area, the general themes can be applicable to a variety of settings. These themes include but are not limited to: the importance of support by family members and friends in crisis situations, the way family members monitor the condition and care given to the patient, and how environmental changes may be interpreted by family members.

Implications for Nursing Research

Further research in the area of parenting in the NICU is warranted. This study has identified aspects of involvement with VLBW infants in the NICU from the mother's stance. It would be beneficial to examine the nurses' perceptions of maternal involvement with the infants in the NICU and compare these two perceptions. Additionally, this study could be strengthened by an investigation of

the father's involvement with their VLBW infants in the NICU. Some of the fathers in this study were eager to discuss their experiences.

Suggestions have been made in this study for strategies to improve the transition phase from the NICU to the SCN environment. If implemented, an evaluation of their effects would be beneficial.

Finally, during this study it was noted that there were inconsistency in the adherence to the components of developmental care. Developmental care has been shown to improve neonatal outcomes and maternal involvement with their infants in the NICU; thus it would be important to investigate the nurse's involvement and support of developmental care strategies.

Summary

The research questions addressed in this study were: What is the process of maternal involvement with their VLBW infants in an NICU? What conditions promote or hinder the mother's involvement? What may account for some of the differences in maternal involvement with their VLBW infants? Grounded theory as proposed by Glaser and Strauss (1967) and further developed by Chenitz and Swanson (1986) was used by the researcher to investigate this question with twelve mothers who had VLBW infants in the NICU for more than twenty-one days. From the data analysis the substantive theory which emerged "Becoming a Mother in the NICU" defines the process through which mothers proceed as they engage in the mothering role in an unfamiliar environment. It defines three stages in the process: (a) caring from the margins, in which the mother as an

interested observer experiences a state of anomie, gives over the care of her infant to the professionals; (b) shifting the balance, as the baby's condition stabilizes, the mother increases her sense of ownership and responsibility; and (c) making progress, where the mother more fully takes on her mothering role.

It was determined from the study that mothers rely on nurses to provide a critical dimension to the care of the neonate which includes facilitating holistic neonatal family centered care. In addition to the literature review of previous research, implications for nursing practice, nursing policy, nursing administration, nursing education, and nursing research were addressed.

REFERENCES

Abel-Boone, H., Dokecki, P. R., & Smith, M. S. (1989). Parent and healthcare provider communication and decision making in the intensive care nursery. *Children's Health Care, 18*, 133-141.

Affleck, G., & Tennen, H. (1991). The effect of newborn intensive care on parents' psychological well-being. *Children's Health Care, 20*, 6-14.

Affleck, G., Tennen, H., Allen, D., & Gershman, K. (1986). Perceived social support and maternal adaptation during the transition from hospital to home care of high risk infants. *Infants Mental Health Journal, 7*, 6-18.

Affleck, G., Tennen, H., Pfeiffer, C., Fifield, J., & Rowe, J. (1987). Downward comparison and coping with serious medical problems. *American Journal of Orthopsychiatry, 57*, 570-578.

Affleck, G., Tennen, H., & Rowe, J. (1991). *Infants in crises: How parents cope with newborn intensive care and its aftermath*. New York: Springer-Verlag.

Affleck, G., Tennen, H., Rowe, J., & Higgins, P. (1990). Mothers' remembrances of newborn intensive care: A predictive study. *Journal of Pediatric Psychology, 15*, 67-81.

Affonso, D. D., Bosque, E., Wahlberg, V., & Brady, J. P. (1993). Reconciliation and healing for mothers through skin-to-skin contact provided in an American tertiary level intensive care nursery. *Neonatal Network, 12*(3), 25-32.

Affonso, D. D., Hurst, I., Mayberry, L. J., Haller, L., Yost, K., & Lynch, M. E. (1992). Stressors reported by mothers of hospitalized premature infants. *Neonatal Network, 11*(6), 63-70.

Als, H., Lawhon, G., Brown, E., Gibes, R., Duffy, F. H., McAnulty, G. & Blickman, J. G. (1986). Individualized behavioral and environmental care for the very low birth weight preterm infant at high risk for bronchopulmonary dysplasia: Neonatal intensive care unit and developmental outcome. *Pediatrics, 78*, 1123-1132.

Als, H., Lawhon, G., Duffy, F. H., McAnulty, G. B., Gibes-Grossman, R., & Blickman, J. G. (1994). Individualized developmental care for the very low-birth-weight preterm infant. *JAMA, 272*, 853-858.

American Academy of Pediatrics Committee on Fetus and Newborn. (1985). Post partum (neonatal) sibling visitation. *Pediatrics, 76*, 650.

Auerbach, K. G., & Walker, M. (1994). When the mother of a premature infant uses a breast pump: What every NICU nurse needs to know. *Neonatal Nurse, 13*(4), 23-29.

Beaumont, N. (1997). Getting the balance right: A model for NICU. *Paediatric Nursing 9*(9), 25-27.

Blackburn, S., & Lowen, L. (1986). Impact of an infant's premature birth on the grandparents and parents. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 15*, 173-178.

Blumer, H. (1969). *Symbolic Interactionism*. Englewood Cliffs, NJ: Prentice-Hall.

Brimblecombe, F. S. W., Richards, M. P. M., & Roberton, N. R. C. (1978). *Separation and Special-care Baby Units*. Philadelphia: J.B. Lippincott Co.

Brooten, D., Gennaro, S., Brown, L. P., Butts, P., Gibbons, A. L., Bakewell-Sacks, S., & Kumar, S. P. (1988). Anxiety, depression, and hostility in mothers of preterm infants. *Nursing Research, 37*, 213-216.

Brown, L. P., York, R., Jacobsen, B., Gennaro, S., & Brooten, D. (1989). Very low birth-weight infants: Parental visiting and telephoning during initial infant hospitalization. *Nursing Research, 38*, 233-236.

Brunssen, S. H., & Miles, M. S. (1996). Sources of environmental stress experienced by mothers of hospitalized medically fragile infants. *Neonatal Network, 15*(3), 88-89.

Catlett, A. T., Miles, M. S., & Holditch-Davis, D. (1994). Maternal perception of illness severity in premature infants. *Neonatal Network, 13*(2), 45-49.

Chenitz, W. C., & Swanson, J. M. (1986). *From Practice to Grounded Theory: Qualitative Research in Nursing*. Menlo Park, California: Addison-Wesley.

Choi, M. (1973). A comparison of maternal psychological reaction to premature and full-size newborns. *Maternal Child Nursing, 2*, 1-13.

Consolvo, C. A. (1986). Relieving parental anxiety in the care by parent unit. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 15*, 154-159.

Corbin, J. (1986). Qualitative data analysis for grounded theory. In W.C. Chenitz & J. M. Swanson (Eds.), *From Practice to Grounded Theory: Qualitative Research in Nursing.* Merlo Park, California: Addison-Wesley.

Dawson, B. (1994). Put the parent and baby first: Nurse/parent relationships in neonatal intensive care. *Professional Nurse, 10*(1), 30-35.

deLeeuw, R., Cuttini, M., Reid, M. (1993). Staff views on parental visiting of very low birth weight infants in neonatal intensive care units-results of a staff inquiry across eleven countries of the European Community. EC-study group on parental involvement in neonatal intensive care. *Journal of Perinatal Medicine, 21*(1), 43-52.

Doll-Speck, L., Miller, B., & Rohrs, K. (1993). Sibling education: Implementing a program for the NICU. *Neonatal Network, 12*(4), 49-52.

Dunham, C., MacDonald, T., & Singhal, N. (1994). Chances and choices: Antenatal information provided to high risk patients before 26 weeks gestation. *Neonatal Intensive Care, 7*(7), 48-51, 64, 66.

Field, T. M. (1977). Effects of early separation, interactive deficits, and experimental manipulation in infant-mother face-to-face interaction. *Child Development, 48*, 763-771.

Flanagan, V., Slattery, M. J., Chase, N. S., Meade, S. K., & Cronenwett, L. R. (1996). Mother's perceptions of the quality of their infant's back transfer: Pilot study results. *Neonatal Network, 15*(2), 27-33.

Fleisher, B. E., VandenBerg, K., Constantinou, J., Heller, C., Benitz, W. E., Johnson, A., Rosenthal, A., & Stevenson, D. K. (1995). Individualized developmental care for very-low-birth-weight premature infants. *Clinical Pediatrics, 34*, 523-529.

Furman, L., Minich, N. M., & Hack, M. (1998). Breastfeeding of very low birth weight infants. *Journal of Human Lactation, 14*, 29-34.

Gennaro, S. (1988). Postpartum anxiety and depression in mothers of term and preterm infants. *Nursing Research, 37*, 82-85.

Gennaro, S. (1991). Facilitating parenting of the neonatal intensive unit graduate. *Journal of Perinatal and Neonatal Nursing, 4*(4), 55-61.

Gennaro, S., Zukowsy, K., Brooten, D., Lowell, L., & Visco, A. (1990). Concerns of mothers of low birth weight infants. *Pediatric Nursing, 16*, 459-462.

Giacoia, G. P., Rutledge, D., & West, K. (1985). Factors affecting visitation of sick newborns. *Clinical Pediatrics, 24*, 259-262.

Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New York: Aldine De Gruyter.

Gottfried, A. W., Wallace-Lande, P., Sherman-Brown, S., King, J., Coen, C., & Hodgman, J.E. (1981). Physical and social environment of newborn infants in special care units. *Science, 214,* 673-675.

Gottfried, A.W. Hodgman, J.E., & Brown, K.W. (1984). How intensive is newborn intensive care? An environmental analysis. *Pediatrics, 292-294.*

Graves, J. K., & Ware, M. E. (1990). Parents' and health professionals' perceptions concerning parental stress during a child's hospitalization. *Children's Health Care, 19*, 37-42.

Griffin, T. (1998). The visitation policy. *Neonatal Network, 17*(2), 75-76.

Griffin, T., Kavanaugh, K., Soto, C. F., & White, M. (1997). Parental evaluation of a tour of the neonatal intensive care unit during a high-risk pregnancy. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 26*, 59-65.

Guillemin, J. H., & Holmstrom, L. L. (1983). Legal cases, government regulations and clinical realities in newborn intensive care. *American Journal of Perinatology, 1*, 89-97.

Hack, M., Klein, N. K., & Taylor, H. G. (1995). Long term developmental outcomes of low birth weight infants. *The Future of Children, 5*, 176-196.

Hamelin, K., Saydak, M. I., & Bramadat, I. A. (1997). Interviewing mothers of high-risk infants. What are their support needs? *The Canadian Nurse, 93*(6), 35-38.

Harrison, H. (1992). Very low birth weight outcomes. *Pediatrics, 89*, 357.

Harrison, H. (1993). The principles of family-centered neonatal care. *Pediatrics, 92*, 643-650.

Hayes,N., Stainton, M.C., & McNeil, D. (1993). Caring for a chronically ill infant: A paradigm case of maternal rehearsal in the neonatal intensive care unit. *Journal of Pediatric Nursing, 8,* 350-360.

Hill, P. D., Brown, L. P., & Harker, T. L. (1995). Initiation and frequency of breast expression in breastfeeding mothers of LBW and VLBW infants. *Nursing Research, 44*, 352-355.

Holditch-Davis, D., & Miles, M. S. (1997). Parenting the prematurely born child. Annual Review of Nursing Research, 15, 3-34.

Hughes, M., McCollum, J., Sheftel, D., & Sanchez, G. (1994). How parents cope with the experience of neonatal intensive care. *Children's Health Care, 23*, 1-14.

Hurst, I. (1993). Facilitating parental involvement through documentation. *Journal of Perinatal and Neonatal Nursing, 7*(2), 80-90.

Jaeger, M. C., Lawson, M., & Filteau, S. (1997). The impact of prematurity and neonatal illness on the decision to breast-feed. *Journal of Advanced Nursing, 25*, 729-737.

Jarrett, M. H. (1996a). Parent partners: A parent-to-parent support program in the NICU part 1: Program development. *Pediatric Nursing, 22*, 60-63.

Jarrett, M. H. (1996b). Parent partners: A parent-to-parent support program in the NICU part 11: Program implementation. *Pediatric Nursing, 22*, 142-144, 149.

Jones, C.L. (1982). Environmental analysis of neonatal intensive care. *Journal of Nervous and Mental Disease, 170,* 130-142.

Kenner, C. (1990). Caring for the NICU parent. *Journal of Perinatal and Neonatal Nursing, 4*(3), 78-87.

Klaus, M. H., & Kennell, J. H. (1982). *Parent-infant bonding* (2nd ed.). Toronto: C.V. Mosby Company.

Kolotylo, C., Parker, N. I., & Chapman, J. S. (1991). Mothers' perceptions of their neonates in-hospital transfers from a neonatal intensive care unit. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 20*, 146-153.

Kuhnly, J. E., & Freston, M. S. (1993). Back transport: Exploration of parents' feelings regarding the transition. *Neonatal Network, 12*(1), 49-56.

Lasby, K., Newton, S., Sherrow, T., Stainton, M. C., & McNeil, D. (1994). Maternal work in the NICU: A case study of an "nicu experienced" mother. *Issues in Comprehensive Pediatric Nursing, 17*, 147-160.

Lee, S. K., Penner, P. L., & Cox, M. (1991a). Comparison of the attitudes of health care professionals and parents toward active treatment of very low birth weight infants. *Pediatrics, 88*, 110-114.

Lee, S. K., Penner, P. L., & Cox, M. (1991b). Impact of very low birth weight infants on the family and its relationship to parental attitudes. *Pediatrics, 88*, 105-109.

Levy-Shiff, R., Sharir, H., & Mogilner, M. (1989). Mother and father preterm infant relationship in the hospital preterm nursery. *Child Development, 60*, 93-102.

Lincoln, Y. S., & Guba, E. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage.

Lindsay, J. K., Roman, L. A., DeWys, M., Eager, M., Levick, J., & Quinn, M. (1993). Creative caring in the nicu: Parent-to-parent support. *Neonatal Network, 12*(4), 37-44.

Lotas, M. J., & Walden, M. (1996). Individualized developmental care for very low-birth-weight infants: A critical review. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 25*, 681-687.

Malkin, J. (1992). *Hospital interior architecture? Creating healing environments for special patient populations.* New York, NY: Van Nostrand Reinhold.

Maroney, D. (1994). Helping parents survive the emotional "roller coaster ride" in the newborn intensive care unit. *Journal of Perinatology, 14*, 131-133.

McDonald-Gibbins, S. A., & Chapman, J. S. (1996). Holding on: Parents' perception of premature infants' transfers. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 25*, 147-153.

McHaffie, H. E. (1991). Neonatal intensive care units: visiting policies for grandparents. *Midwifery, 7*, 193-203.

McKim, E., M. (1993). The information and support needs of mothers of premature infants. *Journal of Pediatric Nursing, 8*, 233-244.

Merestein, G. B. (1994). Individualized developmental care: An emerging new standard for neonatal intensive care units. *JAMA, 272*, 890-891.

Meyer, E. C., Kennally, K. F., Zika-Beres, E., Cashore, W. J., & Oh, W. (1996). Attitudes about sibling visitation in the neonatal intensive care unit. *Archives of Pediatrics and Adolescent Medicine, 150*, 1021-1026.

Miles, M. S. (1989). Parents of critically ill premature infants. Sources of stress. *Critical Care Nursing Quarterly, 12*(3), 69-74.

Miles, M. S., Carlson, J., & Funk, S. G. (1996). Sources of support reported by mothers and fathers of infants hospitalized in a neonatal intensive care unit. *Neonatal Network, 15*(3), 45-52.

Miles, M. S., & Frauman, A. C. (1993). Nurses' and parents' negotiation of caregiving roles for medically fragile infants: Bridges and barriers. *In S. G. Funk (Ed.), Key aspects of caring for the chronically ill: Hospital and home* (pp. 239-250). New York: Springer.

Miles, M. S., Funk, S. G., & Carlson, J. (1993). Parental stressor scale: Neonatal intensive care unit. *Nursing Research, 42*, 148-152.

Miles, M. S., Funk, S. G., & Kasper, M. A. (1991). The neonatal intensive care unit environment: Sources of stress for parents. *AACN Clinical Issues in Critical Care Nursing, 2*, 346-354.

Miles, M. S., Funk, S. G., & Kasper, M. A. (1992). The stress response of mothers and fathers of preterm infants. *Research in Nursing & Health, 15*, 261-269.

Miles, M. S., & Holditch-Davis, D. (1995). Compensatory-parenting: How mothers describe parenting their 3-year-old prematurely born children. *Journal of Pediatric Nursing, 10*, 243-253.

Miles, M. S., Holditch-Davis, D., & Shepherd, H. (1998). Maternal concerns about parenting prematurely born children. *MCN, 23*(2), 70-75.

Miya, P. A. (1989). Imperiled infants: Nurses' role in ethical decision making. *Issues in Comprehensive Pediatric Nursing, 12*, 413-422.

Montgomery, L. A. V. (1989). An anticipatory support program for high risk parents: Follow up results. *Neonatal Network, 8*(3), 31-33.

Montgomery, L. A., Kleiber, C., Nicholson, A., & Craft-Rosenburg, M. (1997). A research-based sibling visitation program for the neonatal icu. *Critical Care Nurse, 17(*2), 29-35, 38-40.

Mooney-Smith, S. (1987). Primary nursing in the NICU: A parent's perspective. *Neonatal Network, 5*(4), 25-27.

Morse, J. M. (1991). Negotiating commitment and involvement in the nurse-patient relationship. *Journal of Advanced Nursing, 16*, 455-468.

Morse, J. M., & Field, P. A. (1995). *Qualitative Research methods for Health Professionals* (2nd ed.). Thousand Oaks, CA: Sage Publications.

Nicholson, A. C., Titler, M., Montgomery, L. A., Kleiber, C., Craft, M. J., Halm, M., Buckwalter, K., & Johnson, S. (1993). Effect of child visitation in adult critical care units: A pilot study. *Heart Lung, 22*(1), 36-45.

Oehler, J. M., Hannan, T., & Catlett, A. (1993). Maternal views of preterm infants' responsiveness to social interaction. *Neonatal Network, 12*(6), 67-74.

Pederson, D. R., Bento, S., Chance, G. W., Evans, B., & Fox, A. M. (1987). Maternal emotional responses to preterm birth. *American Journal of Orthopsychiatry, 57*(1), 15-21.

Perehudoff, B. (1990). Parents' perceptions of environmental stressors in the special care nursery. *Neonatal Network, 9*(2), 39-44.

Philipp, C. (1983). The role of recollected anxiety in parental adaptation to low birth weight infants. *Child Psychiatry and Human Development, 13*, 239-248.

Pinch, W. J. (1990). Five families share their views of ethical decision making in the NICU. *Caring, 9*(12), 12-18.

Pinch, W. J., & Spielman, M. L. (1989a). Ethical decision making for high risk infants: The parents' perspective. *Nursing Clinics of North America, 24*, 1017-1023.

Pinch, W. J., & Spielman, M. L. (1989b). Parental voices in the sea of neonatal ethical dilemmas. *Issues in Comprehensive Pediatric Nursing, 12*, 423-435.

Pinch, W. J., & Spielman, M. L. (1990). The parents' perspective: Ethical decision-making in neonatal intensive care. *Journal of Advanced Nursing, 15*, 712-719.

Pinch, W. J., & Spielman, M. L. (1993). Parental perceptions of ethical issues post-nicu discharge. *Western Journal of Nursing Research, 15*, 422-440.

Pinch, W. J. & Spielman, M. L. (1996). Ethics in the neonatal intensive care unit: Parental perceptions at four years post discharge. *Advances in Nursing Science, 19*, 72-85.

Pridham, K., F., Broome, M., Woodring, B., & Baroni, M. (1996). Education for the nursing of children and their families: Standards and guidelines for prelicensure and early professional education. *Journal of Pediatric Nursing, 11*, 273-280.

Prudhoe, C.M., & Peters, D.L. (1995). Social support of parents and grandparents in the neonatal intensive care unit. *Pediatric Nursing, 21*(2), 140-146

Raines, D. A. (1993). Deciding what to do when the patient can't speak: A preliminary analysis of an ethnographic study of professional nurses in the neonatal intensive care unit. *Neonatal Network, 12*(6), 43-48.

Raines, D. A. (1996). Parents' values: A missing link in the neonatal intensive care equation. *Neonatal Network, 15*(3), 7-12.

Raines, D. A. (1998). Values of mothers of low birth weight infants in the NICU. *Neonatal Network, 17*(4), 41-46.

Raj, V. K., & Plichta, S. B. (1998). The role of social support in breastfeeding promotion: A literature review. *Journal of Human Lactation, 14*, 41-45.

Roman, L. A., Lindsay, J. K., Boger, R. P., DeWys, M., Beaumont, E. J., Jones, A. S., & Haas, B. (1995). Parent-to-parent support in the neonatal intensive care unit. *Research in Nursing & Health, 18*, 385-394.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Scharer, K., & Brooks, G. (1994). Mothers of chronically ill neonates and primary nurses in the NICU: Transfer of care. *Neonatal Network, 13*(5), 37-47.

Scheiner, A. P., Sexton, M. E., Rockwood, J., Sullivan, D., & Davis, H. (1985). The vulnerable child syndrome: Fact and theory. *Journal of Developmental and Behavioural Pediatrics, 6*, 298-301.

Scholmann, P., & Fister, S. (1995). Parental perspectives related to decision-making and neonatal death. *Pediatric Nursing, 21*, 243-247, 254.

Seideman, R. Y., Watson, M. A., Corff, K. E., Odle, P., Haase, J., & Bowerman, J. L. (1997). Parent stress and coping in NICU and PICU. *Journal of Pediatric Nursing, 12*, 169-177.

Shields-Poe, D., & Pinelli, J. (1997). Variables associated with parental stress in neonatal intensive care units. *Neonatal Network, 16*(1), 29-37.

Shiono, P. H. & Behrman, R. E. (1995). Low birth weight: Analysis and recommendations. *The Future of Children, 5*, 4-18.

Stainton, M. C. (1992). Mismatched caring in high-risk perinatal situations. *Clinical Nursing Research, 1*, 35-49.

Stark, J., & Thape, J. (1993). Decision making in neonatal intensive care: A collaboration of parents, physicians, and nurses. *AWHONN's Clinical Issues, 4*, 589-595.

Stauber, S. R., & Mahan, C. K. (1987). Successes and struggles of parents support groups in neonatal intensive care units. *Journal of Perinatology, 7*, 140-144.

Steele, K. H. (1987). Caring for parents of critically ill neonates during hospitalization: Strategies for health care professionals. *Maternal Child Nursing Journal, 16*, 13-27.

Strauch, C., Brandt, S., & Edwards-Beckett, J. (1993). Implementation of a quiet hour: Effect on noise levels and infants sleep states. *Neonatal Network, 12*(2), 31-35.

Swanson, J. M. & Chapman, L. (1994). Inside the black box: Theoretical and methodological issues in conducting evaluation research using a qualitative approach. *In J. M. Morse (Ed.), Critical Issues in Qualitative Research Methods,* (pp. 66-93). Thousand Oaks, CA: Sage Publications.

Thorne, S.E., & Robinson, C. A. (1989). Guarded alliance: Health care relationships in chronic illness. *Image: The Journal of Nursing Scholarship, 21*, 153-157.

Tyson, J. (1995). Evidence-based ethics and the care of premature infants. *The Future of Children, 5*, 197-213.

Watson, J. (1999). *Postmodern nursing and beyond*. Edinburgh, UK: Churchill Livingston.

Wereszczak, J., Miles, M. S., & Holditch-Davis, D. (1997). Maternal recall of the neonatal intensive care unit. *Neonatal Network, 16*(4), 33-40.

APPENDIX A

Telephone Script for Contact with Participant

Hello Ms.

My name is _____, from the Provincial Perinatal Program. I'm calling on behalf of a Janeway nurse, Marion Yetman who is doing a study for her Masters in Nursing. her study is concerned the experiences of mothers while their babies were in the Neonatal Intensive Care Unit. She is working under the direction of Dr. Solberg and Dr. Laryea at the University and Dr. Aziz at the Janeway.

I am asking your permission to give Marion your name and phone number so she can call you about this study.

Thank you.

APPENDIX B

Introduction to the Study

Thank you for agreeing to participate in the study to evaluate the Neonatal Intensive Care Unit experiences of mothers of very low birth weight infants. The results of the study will provide information which can be used by the care givers in the Neonatal Intensive Care Unit in implementing or evaluating a family centered care approach for neonates and their families.

As a participant in the study, you will be interviewed by the researcher. This interview will take approximately sixty minutes. With your permission, the interview will be tape recorded to provide accuracy for transcription. The interviewer may wish to contact you 4-6 weeks later to clarify details from the interview.

Participation in the study is entirely voluntary. You may withdraw from the study at any time. You will be asked to sign a consent form giving permission to be in the study. In order to maintain confidentiality the tapes will be kept in the possession of the researcher in a locked cabinet. The transcripts will not have your name in them.

A copy of the final report will be available to you upon your request. If you have any further question about the study you can contact me, Marion Yetman, at 778-4310.

APPENDIX C

Suggested Topics to Guide the Interview

I am interested in your recent experience as a mother with an infant in the NICU and I would like you to tell me about this.

- Tell me about your first visit.
- Tell me about a typical visit in the day or evening.
- What stands out in your mind about visiting and your involvement with your infant's care?
- Were you able to visit your baby as often as you wanted?
- During the first few weeks, were there decisions made about your baby in relation to the type of treatment that was necessary for survival and did you participate in the decisions?
- How did you feel about the interactions with the doctors, nurses and other staff?
- How did you feel about events, such as infections?
- Did you have concerns about the long term outcomes for your baby and how much did you understand about that?

APPENDIX D

Approval Letter from Human Investigation Committee

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

1998 06 10

TO: Ms. Marion Yetman

FROM: Dr. Jorge Segovia, Acting Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: **Application to the Human Investigation Committee - #98.93**

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled "**Grounded Theory - Very Low Birth Weight Infants in the Neonatal Intensive Care Unit: The Mother's Experience**".

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

Jorge Segovia, MD, M.P.H.
Acting Assistant Dean

cc: Dr. K.M.W. Keough, Vice-President (Research)
Dr. E. Parsons, Vice-President, Medical Services, HCC

St. John's, NF, Canada A1B 3V6 • Tel.: (709) 737-6762 • Fax: (709) 737-5033 • email: rgs@morgan.ucs.mun.ca

APPENDIX E

Approval Letter from the Health Care Corporation

HealthCare
Corporation of St. John's

June 19, 1998

Ms. Marion Yetman
Infection Control Coordinator
c/o General Hospital Site

Dear Ms. Yetman:

Your research proposal HIC 98.94 - Grounded Theory - Very Low Birth Weight (VLBW) Infants in the Neonatal Intensive Care Unit: The Mother's Experience has been considered by the Research Proposals Approval Committee (RPAC) of the Health Care Corporation of St. John's at its meeting on June 18, 1998.

The committee has approved your proposal to be conducted at the Janeway site within the Health Care Corporation of St. John's. This approval is contingent on the appropriate funding being provided and continued throughout the project and on the provision of regular progress reports at least annually to the RPAC Committee.

Yours sincerely,

George Tilley
Senior Vice President
Corporate Affairs

mh
c Patient Research Centre

APPENDIX F

Letter to Program Director - Child Health Program

April 29, 1998

31 Eastview Cres
St. John's, Nf
A1A 3M9

Mrs. Marilyn Pardy,
Program Director, Child Health Program
Janeway Site
Health Care Corporation of St. John's
Janeway Place, St. John's, Nf, A1A 1R8

Dear Mrs. Pardy,

I am a nurse and graduate student in the Masters in Nursing Program, Memorial University of Newfoundland. I am undertaking a research study to examine maternal involvement with their very low birth weight (VLBW) infants while they were in the Neonatal Intensive Care Unit (NICU). It is an attempt to investigate how mothers view their NICU experience and what facilitates or hinders their involvement.

The results of the study will provide information which can be utilized by care givers in the Neonatal Intensive Care Unit in implementing or evaluating a family centered care approach for neonates and their families.

The sample for this study will be the mothers of VLBW infants who have been patients in the Neonatal Intensive Care Units at the Janeway or the Grace site. The study will involve one or two interviews with subjects who agree to participate. The interview setting will be decided by the subjects. An open ended interview format will be utilized and permission will be requested to tape record the interview.

I am requesting your permission to access the subjects through the Provincial Perinatal Program (PPP). On identification of subjects who meet the inclusion criteria, the Co-ordinator of the PPP will be asked to contact the participants.

A copy of the proposal, letter of introduction to the study and the consent form are enclosed for your information. I am available for an interview to discuss further details of the study with you (phone 778-4310, between 0830 and 1630 hours).

Thank you for your anticipated help.

Yours sincerely,
Marion Yetman

APPENDIX G

Letter to Chief of Neonatology

April 29, 1998

Dr. W. Andrews
Chief of Neonatology
Child Health Program
Janeway Site
Janeway Place
A1A 1R8

Dear Dr. Andrews,

I am a nurse and graduate student in the Masters in Nursing Program, Memorial University of Newfoundland. I am undertaking a research study to examine maternal involvement with their very low birth weight (VLBW) infants while they were in the Neonatal Intensive Care Unit (NICU). It is an attempt to investigate how mothers view their NICU experience and what facilitates or hinders their involvement.

The results of the study will provide information which can be utilized by care givers in the Neonatal Intensive Care Unit in implementing or evaluating a family centered care approach for neonates and their families.

The sample for this study will be the mothers of VLBW infants who have been patients in the Neonatal Intensive Care Units at the Janeway or the Grace site. The study will involve one or two interviews with subjects who agree to participate. The interview setting will be decided by the subjects. An open ended interview format will be utilized and permission will be requested to tape record the interview.

This is to inform you of the study which will involve the mothers of some of your patients. The study has been approved by the Human Investigations Committee, Memorial University of Newfoundland, Faculty of Medicine.

If you have any questions or concerns relating to the study, please contact me at 778-4310.

Yours sincerely,

Marion Yetman

APPENDIX H

Letter to Co-ordinator - Provincial Perinatal Program

April 29, 1998

Ms. Cathy Royle
Co-ordinator, Provincial Perinatal Program
Janeway Site
Janeway Place
St. John's, Nf
A1A 1R8

Dear Mrs. Royle,
I am a nurse and graduate student in the Masters in Nursing Program, Memorial University of Newfoundland. I am undertaking a research study to examine maternal involvement with their very low birth weight (VLBW) infants while they were in the Neonatal Intensive Care Unit (NICU). It is an attempt to investigate how mothers view their NICU experience and what facilitates or hinders their involvement.

The results of the study will provide information which can be utilized by care givers in the Neonatal Intensive Care Unit in implementing or evaluating a family centered care approach for neonates and their families.

The sample for this study will be the mothers of VLBW infants who have been patients in the Neonatal Intensive Care Units at the Janeway or the Grace site. The study will involve one or two interviews with subjects who agree to participate. The interview setting will be decided by the subjects. An open ended interview format will be utilized and permission will be requested to tape record the interview.

The study has been approved by the Human Investigating Committee. Mrs. M. Pardy, Program Director, Child Health, has given me permission to access the participants through the Provincial Perinatal Program. I am seeking your assistance in selecting and contacting participants who meet the inclusion criteria.

An introductory letter for the subjects has been included. Once the participants agree to partake in the study, I will contact them regarding the time of the interview.

Thank you in advance for your support.

Yours sincerely,

Marion Yetman

APPENDIX I

Consent To Participate in Nursing Research

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF NEWFOUNDLAND
AND
HEALTH CARE CORPORATION OF ST. JOHN'S

TITLE: A study of mother's experiences during their infants stay in the Neonatal Intensive Care Unit.
INVESTIGATOR: Marion Yetman

You have been asked to participate in a research study which will examine a mother's involvement with her very low birth weight infant while in the Neonatal Intensive Care Unit. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time.

Information obtained from you or about you during this study will be kept confidential by the investigator. All information will be coded and the final report will focus on the central themes which have emerged from interviews with all the subjects. The investigator will be available during the study should you have any problems or questions about the study.

1. Purpose of study:
The purpose of the study is to examine mother's involvement with their very low birth weight (VLBW) infants while they were in the Neonatal Intensive Care Unit (NICU). It is an undertaking to look into how you viewed your NICU experience and what helped or hindered your involvement with your baby. The results of the study will be shared with health care workers in the NICU. It is expected that the information will enhance the care of the infant and family in the NICU.

2. Description of procedures and tests:
In order to get this information, an interview will be required. The interview can take place in an office at the Janeway Hospital, an office at the School of Nursing, Memorial, or in your home. You can decide on the place of the interview. Your permission is requested to tape this interview.

3. Duration of participant's involvement:
You will be interviewed for approximately one hour initially and a return interview may be required to confirm the interpretation of the tapes.

4. Possible risks, discomforts, or inconveniences:
There are no anticipated health risks from your participation in the study. The inconvenience will be the time it takes to do the interview. The risk will be the possibility of you becoming upset, especially if you have had negative experiences or outcomes which were less than desirable. If this should occur, the researcher will stop the interview and discuss the situation with you. If you request further counseling an appropriate referral will be suggested.

5. Benefits which the participant may receive:
Although there are no direct benefits to you as a participant, you may find it helpful to talk about your experiences with an interested party. The results of the research will be available upon request to you.

6. Liability statement:
Your signature indicates your consent and that you have understood the information regarding the research study. In no way does this waive your legal rights nor release the investigator from her legal and professional responsibilities

Signature Page

Title of Project:

A study of mother's experiences during their infants stay in the Neonatal Intensive Care Unit.

Name of Principal Investigator: ***Marion Yetman***

To be signed by participant

I, , the undersigned, agree to my participation in the research study described above.

Any questions have been answered and I understand what is involved in the study. I realise that participation is voluntary and that there is no guarantee that I will benefit from my involvement.

I acknowledge that a copy of this form has been given to me.

(Signature of Participant) (Date)

(Signature of Witness) (Date)

To be signed by investigator

To the best of my ability I have fully explained the nature of this research study. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

(Signature of Investigator) (Date)

Phone Number